“A place where kids like me can be ourselves”: Exploring the meaning of summer camp with adolescents with neurobiological disorders

by

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Abstract

Recreational opportunities are valuable opportunities for physical, social, and emotional development. Summer camp provides youth with the chance to be outside among their peers and learn through play. Unfortunately, social, physical, and institutional barriers often result in the exclusion of high-needs individuals with neurobiological disorders from these camp opportunities and experiences. This research used a qualitative photovoice methodology in order to explore what summer camp means to adolescents with neurobiological disorders.

Teens aged 14-17 at Camp Neuro, a sleepaway summer camp in Ontario, were invited to take photographs of things that were meaningful to them (n=23) followed by an individual interview to contextualise the photographs (n=13). Results suggest that the physical, social, and emotional camp environments are important to youth with neurobiological disorders. Additionally, the opportunity to learn at summer camp was a recurring theme as teens discussed learning skills, learning to make friends, and learning broad life lessons. Overall, the results suggest that youth with neurobiological are successful at summer camp and value their experiences when they are provided with appropriate accommodations and support. Ultimately, the participants expressed that Camp Neuro supported them to ha to be themselves, try new things, and make friends.

Keywords: Neurobiological Disorder, Autism Spectrum Disorder, summer camp, photovoice, recreation

Co-Authorship Statement

Dr. Nicole Yantzi

Dr. Yantzi is the supervisor of this project. She provided ongoing revisions and feedback on this document. Additionally, she was heavily involved in the research method design and the creation of this thesis. Dr. Yantzi will be listed as a co-author on the journal articles, chapters two and three, when they are submitted for publication.

Dr. Shute and Dr. Watson

Dr. Shute and Dr. Watson are the two committee members involved in this project. Both Dr. Watson and Dr. Shute will be given the opportunity to co-author the two articles for publication following the completion of the master's requirements.

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Chapter 1: Introduction

Summer camps are an important and valuable experience for children and teens with many camps providing opportunities to make friends, learn new skills, and gain independence. For young people with neurobiological disorders, most reports of their experiences at summer camp come from caregivers, including parents and guardians, or staff. This thesis explores the meaning of a sleepaway summer camp from the perspective of adolescents with neurobiological disorders such as autism spectrum disorder, attention deficit (hyperactivity) disorder, and Tourette's syndrome. Photovoice was used to gain a richer understanding of the experiences of attending summer camp from the perspective of the campers, adolescents with a variety of neurobiological disorders. In partnership with Camp Neuro (name changed to protect participant identities), a unique Ontario disability-specific summer camp that serves children and adolescents with severe neurobiological disorders, this study represents the views and needs of a population that is often underrepresented in research and particularly in qualitative research (Jurkowski, 2008). This thesis features the experiences of youth with neurobiological disorders with a broad range of social, emotional, and cognitive functioning and explores what their summer camp experiences mean to them.

1.1 Neurobiological Disorders

As defined by the Ontario Human Rights Commission, a disability is any degree of physical disability, infirmity, malformation or disfigurement, a condition of mental impairment or developmental disability, a learning disability or any dysfunction of the process involved in understanding or using symbols or spoken language, or a mental disorder (Ontario Human Rights Comission, 2016). The World Health Organization (2013) further explains disability as a "dynamic interaction between a person's health condition, environmental factors, and personal

factors" (p. 5), acknowledging that disability is fluid and can be considered situation-dependent. The classification "neurobiological disorder" is an umbrella term that refers to a wide range of brain disorders that occurs as a result of an interaction between an individual's biology and neurology. Neurobiological disorders encompass what are considered major psychiatric disorders such as mood disorders and anxiety disorders, as well as childhood developmental disorders such as autism spectrum disorder and Tourette's syndrome (American Psychiatric Association, 2013; Buxbaum, 2013). While the term neurological disorders is more commonly used, neurobiological disorders are a subset that refer more specifically to disorders with a biological basis such as chromosomal disorders. In 2006, Statistics Canada reported that 3.7% of Canadian children under the age of 15 had one or more disabilities (Statistics Canada, 2008). More specifically, 2.5% had a learning limitation (Statistics Canada, 2009). The nature of neurobiological disorders means that many will be captured by that 2.5% with learning limitations, but others may not, such as individuals with anxiety disorders. Some individuals with a neurobiological disorder may have an intellectual disability, characterised by an IQ below 70, though intellectual disability is not inherent to neurobiological disorders (American Psychiatric Association, 2013). Because Canada does not currently use 'neurobiological' as a category of disability, it is difficult to ascertain the actual prevalence among Canadian youth, but the number can be reasonably estimated to be between 2.5% and 3.7% (Blackburn, Read, & Spencer, 2012; Statistics Canada, 2009). For comparison, England estimates the national prevalence of neurobiological disorders to be 3 to 4% among children aged 0-18 (Blackburn et al., 2012).

Due to the wide range of diagnoses that fall under the category of neurobiological disorders, it can be difficult to categorise the effect of these disorders as a whole. Many disorders affect motor skills, behaviour, mood, communication, learning, and/or social skills in varying

degrees and combinations depending on the disorder and the individual (American Psychiatric Association, 2013; Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). For example, autism spectrum disorder tends to affect communication and social skills more severely and consistently with some influence on gross and fine motor skills, while attention deficit disorder primarily affects focus and learning skills (American Psychiatric Association, 2013). Similarly, behavioural and mood challenges associated with oppositional defiance disorder may also be associated with increased learning difficulties for one individual but not for another (Hamilton & Armando, 2008). The current study will use the term neurobiological disorders in order to be consistent and precise with language. However, terminology surrounding this population varies. Therefore, when referring to an external source, this thesis will use the language given by the author(s). It is clear that the population of youth with neurobiological disorder has diverse needs. Additionally, many of the disorders under the term neurobiological are spectrum disorders, meaning there is a continuum of severity even within a single diagnosis and the sub-population is heterogeneous. Neurobiological disorders are complex and can impact numerous parts of a child's life including personal care, social relationships, academic success, and recreation and leisure in the community (American Psychiatric Association, 2013; Dahan-Oliel et al., 2012; Hamilton & Armando, 2008).

Individuals with neurobiological disorders can also be referred to as neurodiverse individuals, the opposite of neurotypical (Jaarsma & Welin, 2012). The term neurodiverse refers to individuals with atypical neurology or behaviours. Neurodiversity, which is the spectrum of human neurology, can be considered normal and natural human variation (Jaarsma & Welin, 2012). The term is linked to the neurodiversity movement, in which activists advocate for the

recognition and respect of individuals with atypical neurology (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Neurodiversity will be discussed in further detail later in this chapter.

1.2 Participation in Recreation and Leisure

Leisure activities such as recreational programming are important components of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (2007). In fact, it is suggested that caregivers place more value on progress in areas such as social participation than impairment-based goals (McDougall & Wright, 2009). The WHO ICF-CY defines participation as involvement in life situations and recognises that for children and adolescents, participation is strongly associated with social involvement (World Health Organization, 2002). In an American study by Hammel and colleagues (2008), individuals with physical and neurological disabilities (n=63) defined participation as an individual and dynamic process that involves interaction between physical, social, cultural, and political environments and communities. The participants of Hammel's study (2008) suggested that participation involves contribution to their social worlds simultaneous with relevant and appropriate supports. Recreational activities can be formal, such as organised sports, or informal, such as playing outside, and for children with disabilities, programming may be integrated or segregated. Participation in any type of recreational activity is considered vital to children's development and is associated with increased physical and mental health, positive social outcomes, and increased quality of life (Dahan-Oliel et al., 2012; King et al., 2003). Children with neurodevelopmental disorders and their families may also experience positive identity outcomes and increased self-esteem if they are able to participate fully in recreational opportunities (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012).

In the 19th and early 20th century, children with disabilities were often segregated in residential institutions, disability-specific schools, and asylums that ensured separation from their typically developing and able-bodied peers (Prince, 2009). With regards to education, for example, children with disabilities were identified as uneducable and therefore denied access to education (Dudley-Marling & Burns, 2014). Following similar civil rights movements for Black people and women, there was a societal shift to recognizing individuals with disabilities as citizens of communities with equal rights in Canada in the mid- to late- 20th century (Prince, 2009). Students with disabilities were then given access to public school but often separated in a specific class because it was presumed they were incapable of following the prescribed structure of Western classrooms (Dudley-Marling & Burns, 2014). Most recently at the turn of the century, the social inclusion movement has led to the majority of children with disabilities spending at least a portion of their day in a regular classroom among typically developing peers (Dudley-Marling & Burns, 2014; Merrells, Buchanan, & Waters, 2019). The evolution to inclusion occurred for a number of reasons including criticisms of the fundraising tactics of disability-specific programs such as capitalization on pity, and the social justice trepidations of segregating children with disabilities (Goodwin & Staples, 2005).

Inclusive programming has widened the availability of educational opportunities as well as recreational programming for families with children with disabilities. Unfortunately, this social change assumes an availability of inclusive programming far above what is realistically available for Canadian families. Additionally, inclusion often overlooks the value of disability-specific spaces where youth with neurobiological disorders can meet and connect with peers who have had similar life experiences (Clark & Nwokah, 2010; Goodwin & Staples, 2005). Additionally, even with a rise in integrated programming, children with neurobiological

disorders often encounter environmental and social constraints that may limit their participation in the activities of their communities (Heah, Case, McGuire, & Law, 2007; Law & Dunn, 1994; Law et al., 1999).

Challenges associated with neurobiological disorders may pose a barrier to involvement in recreational or leisure activities. Individuals may struggle with gross or fine motor skills, which may prevent them or discourage them from engaging in certain activities, in particular sports (Menear & Neumeier, 2015; Mulligan, Hale, Whitehead, & Baxter, 2012). For example, many children with autism spectrum disorder exhibit weakness in posture and movement and therefore may struggle with more physical forms of recreation such as basketball (Kurtz, 2007). Children with neurobiological disorders also frequently struggle with consistent sleep schedules (Mulligan et al., 2012) and fatigue has been identified as a prominent barrier to recreational activity participation (Anaby et al., 2013; Menear & Neumeier, 2015; Mulligan et al., 2012). Youth with neurobiological disorders may also face cognitive barriers. As a result of attention challenges or learning difficulties, children with neurobiological disorders may struggle to follow activity-specific rules particularly when learning a new game (Menear & Neumeier, 2015). Additionally, they may find it difficult to keep track of changing roles in organised sports, such as a switch from defense to offense in a game of soccer (Menear & Neumeier, 2015).

While the pathology of neurobiological disorders does impose some limitations on an individual, many other barriers are the result of the physical and social environment. For youth with neurobiological disorders, the environmental barriers to participation may be less obvious than those barriers for youth with physical disabilities. In conjunction with the limitations of their conditions, the environment may limit a child's ability to participate in recreational or social activities. The physical, social, and institutional environments may constrain participation

in a variety of intersecting ways, resulting in increased social isolation compared to typically developing peers (Heah et al., 2007; Law & Dunn, 1994).

The physical environment includes the natural and built environments. Individuals with neurobiological disorders report lack of available, accessible or affordable transportation as a barrier to participation in recreational activities, particularly among individuals with higher needs or with personal equipment such a wheelchair (Anaby et al., 2013; Mulligan et al., 2012). Youth often need to travel to access recreational activities and therefore stairs or lack of parking close to the desired location were also problematic (Anaby et al., 2013). Physical environments may also interact with the sensory processing of a child with a neurobiological disorder. At playgrounds, for example, a clear circuit and high lookout tower may appeal to the tactile senses of children with autism spectrum disorder (Anaby et al., 2013). Alternatively, children with hyper-sensitivity to visual and auditory stimuli tend to be drawn towards solitary activities such as reading or writing and overwhelming physical environments may significantly reduce their participation (Hochhauser & Engel-Yeger, 2010).

Social environmental factors include the culture individuals are living in as well as the people and institutions with whom they interact (Barnett & Casper, 2001). Negative attitudes or lack of understanding about neurobiological disorders are common barriers that discourage participation in leisure and recreational activities (Anaby et al., 2013; Dahan-Oliel et al., 2012). In a systematic review of peer-reviewed articles discussing barriers to physical activity for people with neurological conditions (n=28), three of the articles reported that staff in recreational facilities were perceived as having limited knowledge regarding the needs of individuals with neurological disorders and were unable to offer or recommend assistance or supports (Mulligan et al., 2012). Some individuals with neurobiological disorders report feeling embarrassed when

exercising in public places (Dahan-Oliel et al., 2012; Mulligan et al., 2012). Others have expressed that negative social attitudes, stigma, and bullying are common barriers to participation (Anaby et al., 2013). Additionally, individuals with neurobiological disorders may have difficulty navigating social situations and may experience increased stress in recreational programs that demand social understanding, such as organised sports (Menear & Neumeier, 2015).

Parents and children have expressed that changes to disabling environments would allow for more full and meaningful participation for young people with disabilities (Law et al., 1999; Prellwitz & Tamm, 2000). Anaby and colleagues (2013) conducted a scoping review of 31 articles to investigate what is known about the impact of the environment on participation in out-of-school activities for youth with disabilities. They reported that attitudinal barriers are more substantial than physical barriers as they often prevent changes to the physical environment (2013; McColl et al., 2005). Institutional environments have a similarly overarching effect on accessibility and inclusion. Institutional environments encompass policies and services at a systems level (Anaby et al., 2013). In Denmark, for example, children with cerebral palsy participate in recreational activities to the same extent or more than children in the general population (Anaby et al., 2013). This statistic suggests that environmental barriers are far more limiting than the symptoms of the disorders themselves. Denmark's positive social attitude towards disability and disorders is reflected in policy, services, and supports, which has significantly reduced and removed barriers to participation (Anaby et al., 2013). Institutional barriers may also include costly financial policies. Caring for a child with a disability carries both direct out-of-pocket costs for things such as services, behavioural and cognitive therapies, and indirect costs such as lost wages from additional caregiving needs (Plumb et al., 2015). After

covering basic needs associated with neurobiological disorders, caregivers may be unable to afford the fees associated with many recreational programs.

1.3 The need for disability-specific camps .

Summer, in particular, marks a period of high demand for recreational disability programming. Many parents have commented on the stress associated with appropriate care for their children with disabilities when school is out, routines change and there is a lack of supportive care (Corbett et al., 2014; Jones, 2003; Schick Makaroff, Scobie, Williams, & Kidd, 2013). The unstructured summer months are often daunting for children with neurobiological disorders and their caregivers, and many children may experience a regression in skills, prevalent negative emotions, and increased maladaptive behaviours (Duncan, 2016). Summer camps provide an opportunity for youth to connect with other children their age and give them a break from their caregivers, and caregivers a break from their children. For parents with a child with a neurobiological disorder, there exist some options when selecting a summer camp including day camps, where parents drop children off in the morning and pick them up later in the afternoon, or sleepaway camps (Our Kids, 2014). There are also some family camps, where the entire household can attend camp together (Our Kids, 2014).

Many of these camp types are also offered as inclusive or disability-specific programs. However, the supports needed for a child with a neurobiological disorder or their antisocial behaviours may disqualify them from participating in inclusive recreational activities or pose additional barriers (Jones, 2003). There is often an increased cost to appropriate programming for youth with additional behavioural challenges due to increased staffing demands and if there is limited access to funding, the financial barrier may be insurmountable (Anaby et al., 2013). Other programs may have rigid or non-inclusive policies within an integrated program that

restricts the participation of some children with neurobiological disorders who have extreme antisocial behaviours, unmanageable self-injurious behaviours or needs that the program is unable or unwilling to meet (Anaby et al., 2013). For example, Easter Seals camps, which are well-established sleepaway camps for children with a variety of disabilities, will not accept any campers who exhibit inappropriate behaviour to themselves or others or who are unable to eat meals and sleep without being disruptive (Easter Seals, n.d.). While aggression is not inherent to neurobiological disorders, it is often a symptom. A study involving children and adolescents with autism spectrum disorder reported that 68% of the study sample had demonstrated aggression to a caregiver and 49% to a non-caregiver (Kanne & Mazurek, 2011). Aggression and similar behavioural challenges are prevalent in young people with neurobiological disorders, but services and programs equipped to accommodate these needs are lacking, leaving caregivers dissatisfied and with few options (Hodgetts, Nicholas, & Zwaigenbaum, 2013; McGill, Papachristoforou, & Cooper, 2006).

When inclusive environments fail to accommodate an individual with a neurobiological disorder, specialised programs may provide a unique opportunity for increased support as well as interaction with peers with similar disorders. A systematic review of 19 studies exploring participation in recreational leisure activities for children with neurodevelopmental disabilities found that engaging in activities with typically developing peers as well as peers with disabilities had positive effects on quality of life (Dahan-Oliel et al., 2012). Their results suggest that even with the rise of more integrated services and programs, the availability of disability-specific programming should be maintained as an available option. Teens at a disability-specific residential summer program for youth with physical and learning disabilities explained that meeting others who share common life experiences with themselves supported the development

of their disability identity (Goodwin & Staples, 2005). The opportunity for young people to be around others with a disability may supply some of the disability culture that they lack in their daily lives at home or school (Clark & Nwokah, 2010).

For many neurodiverse youth, their conception of successful participation involves some degree of independence (Heah et al., 2007). Residential, or sleepaway camps, provide a greater degree of independence for youth. Emotional development and well-being, independence, and autonomy are especially relevant outcomes for adolescents (Dahan-Oliel et al., 2012). In Goodwin and Staples' study (2005) at a Canadian residential camp for teens with disabilities, many of the teens expressed that the period of time away from their families and/or caregivers "required them to be self-reliant" (p. 169). For adolescents with neurodevelopmental disorders in particular, independence is not always fostered and rarely assumed (Dahan-Oliel et al., 2012). In a systematic review by Dahan-Oliel and colleagues (2012) of leisure program participation in youth with neurodevelopmental disorders, researchers found that a number of studies reported positive independence and/or autonomy outcomes for children with neurodevelopmental disorders. The nature of summer camps, and sleepaway programs in particular, provide an ideal environment to foster independence and support autonomy for young people with neurobiological disorders.

1.4 Respite.

As a result of the many barriers to recreational programming, many families' support options are limited to respite services. Respite is a break for families and caregivers from the physical and emotional demands of caring for an individual with a disability (Autism Ontario, 2018). Respite services may have a primary or secondary purpose. A primary purpose would be to provide the family with relief from caregiving and a secondary purpose would be services that

aim to meet the needs of the individual with a disability and respite occurs as a by-product (Robinson & Stalker, 1993). Most recreational programs would fall into the secondary model of respite with programming for youth with disabilities being the focus and relief for caregivers a secondary result. In particular, individuals with neurobiological disorders who have experienced behavioural crisis rely heavily on the secondary model of respite services in order to access recreational activities (Weiss & Lunsky, 2010).

A Canadian study of 40 mothers of children with intellectual disabilities who had experienced a mental health or behavioural crisis in the past year investigated parents' use of services as they related to their child (Weiss & Lunsky, 2010). The study suggests that while there are barriers to accessing respite services, the majority of caregivers who needed respite received it (Weiss & Lunsky, 2010). Alternatively, a Calgary study of caregivers of individuals with autism spectrum disorder and aggression (n=9) reported an inability to find and maintain respite care (Hodgetts et al., 2013). The discrepancy between the two studies suggests that aggression may be a significant barrier to accessing respite services and that youth who have externalized aggressive behaviours may be further excluded from participation.

The availability of respite care is associated with lower stress levels in caregivers in many studies (Whitmore, 2016), highlighting its importance as a support for families caring for a child with complex neurobiological disorders. Individuals who are using formal respite services are likely to have a high baseline level of stress. It is only with adequate respite care that stress levels will decrease and what constitutes as adequate is highly subjective for each family (Whitmore, 2016). As a result, individuals with higher needs, more complex behaviours and displays of aggression are less likely to have access to formal respite care and therefore their caregivers are likely to maintain high levels of stress (Hodgetts et al., 2013; Whitmore, 2016). Specialised

respite and/or recreational programs that are equipped to address complex needs are clearly valuable both to individuals and their families. While the majority of caregivers that have received respite care have reported satisfaction with the services received, benefits to the child have not been well-studied (Pollock, Law, King, & Rosenbaum, 2001).

1.5 Rationale

There is extensive research concluding that summer recreation programming is valuable for children with neurobiological disorders; however there has been minimal insight into the value of disability-specific spaces from the camper's point of view, specifically youth with cognitive or neurobiological disorders. The vast majority of existing literature on the value of respite services and summer programming is reported by caregivers or support workers (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012; Murphy & Verden, 2013; Walker, Barry, & Bader, 2010).

Additionally, there has been little exploration in the literature into the actual role of the camp environment on the experience of camp participants (Clark & Nwokah, 2010). Many of the studies that measured camp outcomes were pre- or post- reported, resulting in data that do not capture the overall camp experience (Clark & Nwokah, 2010). While these programs often operate as a respite service, a valuable support for families and caregivers of children with a variety of disorders, they should also be considered for their recreational and life skills values to campers. None of the research exploring the value of respite in families with children with neurobiological disorders has considered the experiences or perspectives of the child. Clark and Nwokah (2010) express the need for qualitative research to explore the importance of disability culture and peer groups, and the value of play as fun or motivating.

Finally, with the rise of inclusionary programming, the meaning of exclusive disability-specific spaces as recreational opportunities for young people has been minimised, particularly

as it relates to youth with neurobiological disorders (Goodwin & Staples, 2005). As previously detailed, multiple studies have reported positive identity outcomes as a result of summer programming involvement (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012; Goodwin & Staples, 2005). However, no study has focused on the meaning of disability-specific recreational programming to youth with neurobiological disorders from their perspectives.

1.6 Research Question

In light of the limitations in the existing literature, this thesis explores the following research question: "How do adolescents with neurobiological disorders at a disability-specific sleepaway camp in Ontario make meaning of their summer camp experiences?" For the purpose of this research, an adolescent refers to an individual aged 14-17, as per the age restrictions for the selected Camp Neuro's Teen Program. Campers at Camp Neuro must have an established diagnosis of a neurobiological disorder in order to attend. Admission to summer camp was considered sufficient support for the inclusion criteria of having one or more neurobiological disorders.

Language is socially charged, particularly in the field of disability studies, and therefore the language used in the research question has been carefully chosen. The phrase disability-specific is used instead of segregated due to the negative connotations and history of social injustice embedded in the word. Additionally, the word sleepaway was chosen in place of residential. This project pursued a participatory methodology in order to work closely with youth with neurobiological disorders as co-creators of knowledge. Sleepaway is the vocabulary that is most familiar to the participants of this project.

1.7 Theoretical Framework

Working with adolescents with neurobiological disorders, this study is situated within the 'new' disability paradigm, which is a part of critical disability theory. This paradigm asserts that disability is not individual impairment, but rather is a product of the interaction between individuals with impairments, the environment, and society (Gabel & Peters, 2010; Schalock, 2004). Within the disability paradigm, the underlying ontology operates under an assumption that reality is created by individuals. Ontology is a theoretical concept that aims to establish a description of reality (Crotty, 1998). It is particularly important in critical disability theory because it challenges a universal truth and focuses on the individual nature of disability and how these unique experience shape truth and reality.

By aiming to gain an understanding of the meaning of summer camp for teens with neurobiological disorders, the researcher of this thesis recognises that this knowledge is mutually constructed by the individuals, their environment, and society in social constructivism. The epistemology of this research, that is how we know what we know, comes from a critical paradigm. Both reality and knowledge are socially constructed and influenced by systems of oppression. For this thesis research, it was crucial to acknowledge the systems of ableism and social understandings of disability and impairment that shape the realities of youth with neurobiological disorders (Crotty, 1998). Ableism refers to the ways in which society turns different abilities into disabilities and is defined as discriminatory conduct towards individuals based on physical or cognitive abilities (Harpur, 2012).

Situated within the new disability paradigm, this study approaches research using critical theory, specifically critical disability theory. The 'new' disability paradigm is largely informed by the social model of disability (Gabel & Peters, 2010). Disability studies has historically been

split into two dominant spheres; the medical and the social. The divide is the result of the different factors that affect living with a diagnosed disorder or disability, an attempt to consider the medical complications of living with a disability as well as the construction of a disability identity within a largely ablest society. The evolution of the new disability paradigm is an effort to shift the conversation of disability away from the tragic connotation that is often applied. (Gray, 2009).

Traditionally, the medical model has dominated and shaped disability discourse. The medical model was popularised in the 20th century and was driven by health care professionals and researchers who viewed disability as an individual deficit or functional limitation (Abberley, 1987; Hiranandani, 2005). Disability was positioned as a biological problem that interferes with an individual's ability to succeed in our society (Abberley, 1987). The medical model saw disability as a problem located in an individual body that should be cured, fixed, or eliminated (Abberley, 1987; Berghs, Atkin, Graham, Hatton, & Thomas, 2016). As a result, individuals with incurable, chronic, or pervasive disabilities were themselves problematic while able-bodied, neurotypical individuals were considered normal and normalcy was both desired and favoured.

The social model of disability emerged largely as a response to the problematic medical model. Criticism of the medical model focused on the lack of consultation with individuals with disabilities and a reduction of disability to objective, largely physical, impairments (Hiranandani, 2005). Activism by people with disabilities in the early 1970's pushed back on the medical model, reclaiming the narrative from health-care professionals and advocating for person first language (Berghs et al., 2016). The assertion is that an individual with a disability exists in a social system where they are oppressed, and their impairment is socially constructed. The social

model of disability will largely inform the approach of this thesis to disability research and will be used as a foundation for the theoretical framework.

The underlying principles of the social model of disability provide the foundation for critical disability theory. These principles state that disability is a social construct, disability can be characterised by an interaction between impairment and the social and physical environment, and that the social disadvantage of peoples with disabilities is the result of an ablest society (Hosking, 2008). According to the social model of disability, it is the ways in which society constructs social diversity that in turn constructs disability (Harpur, 2012). Critics have identified some weaknesses in this model, specifically that it is simplistic and idyllic in nature (Gray, 2009; Harpur, 2012; Shakespeare, 2016). The social model of disability so vehemently opposed the medical model that it has largely discounted the role of individual impairment entirely (Shakespeare, 2016). It is undeniable that there are internal limitations as a result of many disabilities, including neurobiological disorders. Inclusion for individuals with disabilities requires not just the elimination of discrimination, but additional resources and alternate accommodations in order to make participation truly accessible (Shakespeare, 2016).

Critical theory is an informative framework for this thesis research. The theory evolved from Western Marxist scholars who aimed to expose the role of dominant social forces that contribute to oppression (Hosking, 2008; Kincheloe & McLaren, 2002). Additionally, critical theory is concerned with systems of power and oppression between groups and individuals of a society, aiming both to understand and uncover these systems as well as provide goals or guidance for societal change (Hosking, 2008; Kincheloe & McLaren, 2002). Critical disability theory is the subset of critical theory that focuses on the systems of oppression affecting people with disabilities. The theory includes a version of the social model of disability as it has been

argued that a social approach to disability is best developed using the concept of oppression (Hosking, 2008; Abberley, 1987). The emergence of critical disability theory specifically frames disability issues with regards to ableism and the privilege of being able-bodied and able-minded in society. Ableism refers to the prejudice, discrimination and discounting of persons with disabilities (Harpur, 2012). Critical disability theory marries the subject areas of disability studies and critical theory and suggests that approaches to disability research should be framed by a theory of the oppression of the body (Abberley, 1987; Hiranandani, 2005).

In addition to the more general critiques, critical theory and the social model of disability also have limitations as they apply specifically to this thesis. Critical disability theory has traditionally been applied to physical impairments whereas this research is engaging young people with neurobiological disorders. Neurobiological disorders tend to be invisible impairments that lack unifying physical identifiers. Individuals, particularly children, with neurobiological disorders are often labeled as odd or difficult and subject to different discrimination, alienation or oppression than children with visible physical disabilities such as those in wheelchairs (Solomon, 2012). Similarly, neurobiological disorders do not have a standard treatment plan that can be applied to every child. While there are medications to mitigate some symptoms as well as behavioural and occupational therapies, there is no single assistive device that makes manoeuvring the world with a neurobiological disorder easier the way a wheelchair does for individuals with mobility impairments. As a result of the difference in accommodation and intervention outcomes, much of the discourse in critical disability theory does not address the concerns of those with cognitive and neurobiological disabilities. Additionally, the framing of ‘disability’ as an inclusive category is challenged by many individuals with neurobiological disorders (Berghs et al., 2016). Neurodiverse individuals and

those diagnosed with neurobiological disorders many not consider themselves to be disabled or may challenge the traditional idea of biological impairment (Berghs et al., 2016). While critical disability theory aims to identify and move to dismantle systems of oppression, this becomes challenging when many who need accommodation do not ascribe to the traditional idea of disability and when each individual impairment is so unique (Shakespeare, 2016).

It is also important to acknowledge that there are intrinsic limitations for children with neurobiological disorders even outside of a social system. A study of 250 children and adolescents with autism spectrum disorder in Hamilton and Toronto reported 51% of participants demonstrated self-injurious behaviours over their lifetime (Duerden et al., 2012). To ignore this would be to minimise the dangerous risk of self-injurious behaviours that are often seen in individuals with neurobiological disorders. Additionally, the fact that these behaviours are within a social system that stigmatises self-injurious behaviour makes managing even more difficult due to lack of understanding. The unique nature of neurobiological disorders poses a challenge to critical disability theory. Neurodiversity is a crucial aspect of the theoretical framework of this thesis that emerges from the limitations of critical disability theory. Neurodiversity maintains the core tenets of critical disability theory but is rooted in cognitive disability and addresses some of the challenges previously detailed.

Neurodiversity conceptualises neurobiological disorders as natural human variation in neurological capacity and advocates for value and recognition for this natural diversity (Goodley & Runswick-Cole, 2010; Jaarsma & Welin, 2012). As described earlier, the medical model aims for normalcy and has a cure-oriented approach to disability (Cascio, 2012; Kapp et al., 2013; Ortega, 2009). Neurodiversity developed from individuals with neurobiological disorders themselves, who have asserted that neurobiological disorders are not diseases to be cured, but

rather are unifying characteristics of a vibrant community with unique abilities and complex identities (Griffin & Pollak, 2009; Kapp et al., 2013; Ortega, 2009; Silverman, 2015; Solomon, 2012). The pushback on the medical community is similar to that seen from other disability groups such as the Deaf community or Little People of America, whereby members of a given community reframe the narrative typically dominated by health professionals to describe the vibrancy of culture and identification that accompanies perceived disabilities (Jaarsma & Welin, 2012; Ortega, 2009; Solomon, 2012).

The movement is situated in the view that the pathologies of neurobiological disorders are inseparable from the identity of the individual (Kapp et al., 2013). The inclusion of neurodiversity theory has been particularly prominent in autism spectrum disorder literature and is aligned with the social-constructionist view that the identity of persons with disabilities is the result of social construction and does not exist in isolation (Jaarsma & Welin, 2012). Lawson (cited in Jaarsma & Welin, 2012) is an autism spectrum disorder advocate and scholar and explains the link between neurodiversity and social construction, saying "... only as a society gains an understanding of an individual and their cognitive difference and also use the understanding to inform appropriate interventions, will that individual's 'disability' be less disabling" (p. 28).

New advocacy is emerging from individuals with neurobiological disorders themselves who are moving away from the view of disorder as a disease to neurodiversity as an identity and a culture. Additionally, they are re-claiming the narrative from parents, caregivers, and medical professionals who previously dominated the conversation (Kapp et al., 2013). Incorporating neurodiversity into the theoretical framework of the current study falls under the guiding theme of critical theory, which involves challenging the systems of oppression in society that view

neurodiversity as disease. Neurodiversity challenges the ideology that individuals with neurobiological disorders should solely be subjects in research and insists on incorporating their personal experiences as active research participants in academic research.

However, neurodiversity does have some limitations that must be considered including assuming a certain level of privilege. Because it arises primarily out of the experiences of individuals living with autism spectrum disorder, the movement largely excludes the voices of those individuals who experience the most impairment or those who have the greatest levels of need. One mother of a daughter with autism spectrum disorder expresses this conflict between who needs neurodiversity and who can contribute to the conversation like this: "I'd like nothing more than for my daughter to develop the kind of consciousness that would allow her to join the neurodiversity movement" (Franklin cited in Solomon, 2012, p. 283). The neurodiversity movement is biased towards higher developmental individuals who have appropriately high skill levels in both receptive and expressive language (Kapp et al., 2013) as well as developed skill in areas such as social engagement and cognition. The theory may, in these cases, trivialise individuals' experiences or overestimate the ability of families to cope with some of the more harmful behaviours.

The theories used to frame this thesis are imperfect. However, they remain important and informative, providing a richness to this thesis research that would not be otherwise achievable. It is crucial to remain aware that disability is a complex phenomenon requiring not only social intervention, but engagement with the medical sphere as well (Shakespeare, 2016). The theoretical framework of this study promotes more meaningful emerging narratives and has provided a solid foundation from which the methodology for this research was logically developed.

This theoretical framework leads to consideration of a methodology that is more empowering for the participants themselves. It is crucial that research feature the voices of those with disabilities if it intends to pursue meaningful change. Understanding the perspectives of youth with neurobiological disorders is valuable for the continued development of accessible and fun recreational programs for this population. As a result, this thesis pursued a qualitative community-based methodology, photovoice, in order to collect rich description of the participants' experiences. Further, an arts-based method was selected in order to address power imbalances, written and verbal communication deficits, and to promote engagement with a vulnerable population.

1.8 Methodology: Photovoice

Photovoice, a qualitative visual method, was used for this thesis project. Originally, photovoice invited participants to take pictures to contextualise and describe their health (Wang & Burris, 1997). The process involves participants taking photographs on a given topic followed by a facilitated discussion to allow participants to reflect on the images they took and to provide contextual insight on the photographs for the researchers (Wang & Burris, 1997). Photovoice projects also typically make use of the photographs and discussions to help participants advocate for social action or policy change (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016; Wang & Burris, 1997). The photovoice literature suggests that it is an effective methodology for engaging vulnerable populations and groups that are often underrepresented by academic research, such as young people with neurobiological disorders (Ha & Whittaker 2016). The methodology is rooted in Freire's theory of critical consciousness, which explores the use of visual material as a tool to identify social and political constructs that maintain a community's marginalisation (Freire, 2000; Wang & Burris, 1997). This thesis is framed by critical disability theory and

neurodiversity. Photovoice is well suited to this project as it allows the participants, teens with neurobiological disorders, to capture their unique and personal realities and drive the narrative (Wang & Burris, 1997).

Photovoice has been used in a number of recent studies engaging people with neurobiological disorders (Cheak-Zamora, Teti, & Maurer-Batjer, 2018; Ha & Whittaker, 2016; Jurkowski, 2008, 2008; Teti et al., 2016). The involvement of individuals with cognitive disabilities in participatory research is limited in the literature, though recent publications suggest that it is emerging and growing (Cheak-Zamora et al., 2018; Ha & Whittaker, 2016; Teti et al., 2016). By using photovoice in this research project, adolescents with neurobiological disorders were able to present their individual perspectives on their summer camp community, a disability-specific sleepaway summer camp in Ontario (Wang & Burris, 1997). Additionally, photovoice is an opportunity to empower youth as active participants in the research project and results in research that is driven by the participants with neurobiological disorders that it features (Greco, 2015).

For this thesis, adolescents at a camp for youth with complex neurobiological disorders in Ontario were invited to take pictures of what camp means to them. The study site, Camp Neuro, serves campers aged six to 17 with a variety of complex neurobiological disorders including autism spectrum disorder, Tourette's syndrome, attention deficit (hyperactivity) disorder, and obsessive-compulsive disorder. Campers come for a two-week session and engage in a variety of camp activities including swimming, rope climbing, bike riding, and arts and crafts. Camp Neuro offers four sessions over the summer; two designated for male campers and two for females.

Following approval from Laurentian University's Research Ethics Board (Appendix F) and the directors of Camp Neuro, participant recruitment began using an opportunistic sampling

strategy (Jupp, 2006). Caregivers of adolescents enrolled in the 2018 summer program at Camp Neuro aged 14-17 were sent an information letter and letter of consent (Appendix A and B). Participants of all genders and from all four sessions of camp were invited to participate. For potential participants who received parental consent, the researcher also sought participant assent. In order to ascertain assent, teens were introduced to the study during their first few days at camp (Appendix C). The researcher met with potential participants individually, explained what participation involved, and asked whether they would be interested in being involved. The teens at Camp Neuro have a spectrum of cognitive abilities and communication skills. A variety of methods were used to ensure that participants understood what was being asked of them, including written, verbal and visual instructions and a calendar with pictures to help them to conceptualise their time at camp (Appendix D). It was also clearly emphasised that their participation was voluntary with the option to withdraw at any time. Only those with both parental consent and ongoing assent were included in the final thesis.

Data collection involved two interconnected phases. Phase one involved inviting the participants to take photographs around camp, followed by phase two for which they were invited to contextualise and discuss their photographs in a one-on-one conversational interview. Both phases were prompted by the question "What does summer camp mean to you?". For phase one, participants were provided with digital cameras and asked to capture photographs to show what they like about camp as well as what they find challenging. The digital cameras were kept in the office of Camp Neuro and participants were able to sign out a camera for an hour at a time. This allowed flexibility in when the participants took their photos. Clear rules for appropriate photo-taking were printed out on small cards to give to the participants along with the camera. Rules included the expectation that participants would remain on camp property, protect their

personal safety, and protect the privacy of people at camp by omitting faces from their photographs. Participants were allowed to take as many photographs as they wanted and were permitted to sign the camera out as many times as desired.

Phase two of data collection involved an individual interview. Participants who participated in phase one were not obligated to participate in phase two. Using the same approach as with the cameras, participants who wanted to take part in an interview were invited to sign up on a day and time of their choosing. The participants were asked to tell the researcher about their photos, and follow-up questions and probes were used as needed (Appendix E). Originally, it was intended that participants would select five photographs to discuss during their interview. Very early on in the data collection process, it was clear that many of the teens wanted to talk about all of the photographs they took and were resistant to being limited to five. In response to their feedback, the interview process changed to allow the participants to talk about whichever photographs they wanted and as many as they wanted. The flexibility of photovoice allowed the participants to make many of the decisions for data collection themselves. Participants were able to use the camera, the data collection tool, at their own pace and in their own environment as well as select which photographs they wanted to take and discuss, prioritizing their narratives and stories (Catalani & Minkler, 2010; Teti et al., 2016; Wang & Burris, 1997). At the end of the interview, participants were invited to choose their own pseudonyms. Participants who did not take part in phase two were assigned a participant number.

The data produced by this project included photographs, audio-recorded interviews, and verbatim transcripts. In many photovoice projects, visual data are either not analysed by the researchers or the details of handling visual data are difficult to ascertain (Ha & Whittaker, 2016). Because of the potential verbal and non-verbal communication deficits of adolescents

with neurobiological disorders, this project analysed the visual data alongside the interviews. As a result, a different weight was applied to the photographs during analysis. Interview transcripts were coded first, using a semantic, inductive approach to thematic analysis guided by Braun and Clarke's six step approach (2006). Following initial analysis of all interviews, all of the photographs were coded for focus, what the photograph appeared to be of, and location, where the photograph was taken. Photographs taken by teens who took part in only phase one and those who participated in both phases one and two were all included in the analysis. These pre-determined factors and the outline for handling visual data in conjunction with interview data were described by Ha and Whittaker (2016; Bock, Isermann, & Knieper, 2011). Following initial coding of both sets of data, the two were considered in conjunction in the development and refinement of themes. By using two sets of interconnected data, triangulation was achieved, and the overall rigour of the study was enhanced (Creswell, 2007; Denzin & Lincoln, 2005; Ha & Whittaker, 2016). Unlike many photovoice projects, both the photographs and the interview transcripts were handled as equally important in an effort to more accurately represent the participants' views. Data analysis was supported by QSR NVIVO®, a qualitative research software tool.

The photovoice methodology provided a flexible and supportive method to actively engage youth with neurobiological disorders in research. Photovoice allowed the teens to drive the data collection and shape the direction of the research according to what was most important to them. The method also provided the researcher the flexibility to accommodate communication, cognitive, and motor challenges and gave the participants a tool to express their creativity. The result was an engaging project that showcases the experiences of youth with neurobiological disorders at a specialised sleepaway camp in Ontario.

1.9 Reflexivity

Horkheimer, one of the original critical theorists, acknowledged that in studies framed by critical theory, a researcher often engages in an interactive relationship with the research subject (1972) without the traditional claim of objectivity (Hosking, 2008). My research has been inspired by my personal work with the study site, Camp Neuro. I have worked with Camp Neuro for the past four years in a variety of roles and capacities. Presently, I work as a staff supervisor, supporting counselors as they deliver respite care and recreational programming both over the summer and weekends throughout the school year. During this research project, I occupied two roles; staff and researcher. It is important to note that during data collection I was not directly working with the teens as a paid member of staff.

As this thesis makes use of photovoice methodology, positionality and reflexivity are important aspects. Rooted in critical theory, I acknowledge that I am an active participant in the research process and that my involvement will have an influence on the outcomes and results of the project. I myself am a neurotypical individual and not a member of the population featured by this research project. I acknowledge that my social position will, in many cases, be different from that of my participant. I am an English speaking, white, female as well as a graduate student in a traditional academic setting. I am also viewed as a person of authority to many of the participants in this study as I have worked with them as a service provider and have held a role close to that of a caregiver. Additional reflexive practices described below were used to increase the mutual process of research that is intended by a participatory research approach (Finlay, 2002).

This thesis also incorporates interpretive inquiry, acknowledging that a researcher has an influence on the pursuit of knowledge and, as such, reality is influenced and constructed to some

extent by theory and society (Smith, 2008). My experiences, knowledge, and position within various systems of power are all important to acknowledge and I made a concerted effort to acknowledge these factors before beginning this research and throughout the process. On a more personal level, my love of camp and my observations of the positive effects that it has on children with behavioural disorders makes me a very passionate researcher. I have seen many children and teens make lifelong friends at summer camp and develop self-esteem through skill building and unconditional support. Through multiple reflexivity practices including memoing and critical reflection throughout the entire thesis process, I have aimed to ensure that the nature of this study remains exploratory rather than affirmative and represent the experiences of the participants rather than my ideas of camp. Memoing did not follow a prescriptive outline but rather memos were recorded whenever an idea, thought, impression, or feeling needed to be written down (Birks, Francis, & Chapman, 2008). The memos were reviewed regularly, and memos associated with photographic or interview data were also imported in QSR NVIVO®. This research process was also bookended by critical reflection processes. Reflexivity allowed me to reflect on my position as it related to this project and to remain aware of how this lens impacted the collection, analysis, and interpretation of the data (Birks, Francis, & Chapman, 2008) The use of reflexive practices helped to ensure that this study remained an exploration of the participants' feelings and thought on summer camp, rather than a hypothesis driven project looking to affirm the benefits of camp.

1.10 Overview of the Articles

The results of this research project will be presented in the form of two academic articles. The first article, found in Chapter 2, will focus on theme one: the camp environment. This article will explore how the participants discussed the physical, social, and emotion environments of

Camp Neuro and the meanings of each. This article will be submitted to the academic journal Children, Youth, & Environments. The second article, Chapter 3, will explore the second major theme: what teens with neurobiological disorders have learned at summer camp. Participants discussed the social skills they gained at Camp Neuro, their personal growth, and the greater life lessons that summer camp had taught them. This article will be submitted to Disability & Society. The themes and sub-themes discussed in there two articles are represented in Figure 1. The thesis ends with Chapter 4, which provides a discussion of the thesis and its results in its entirety. Additionally, Chapter 4 will cover the ongoing knowledge translation activities including the cumulative social action component of the photovoice project.

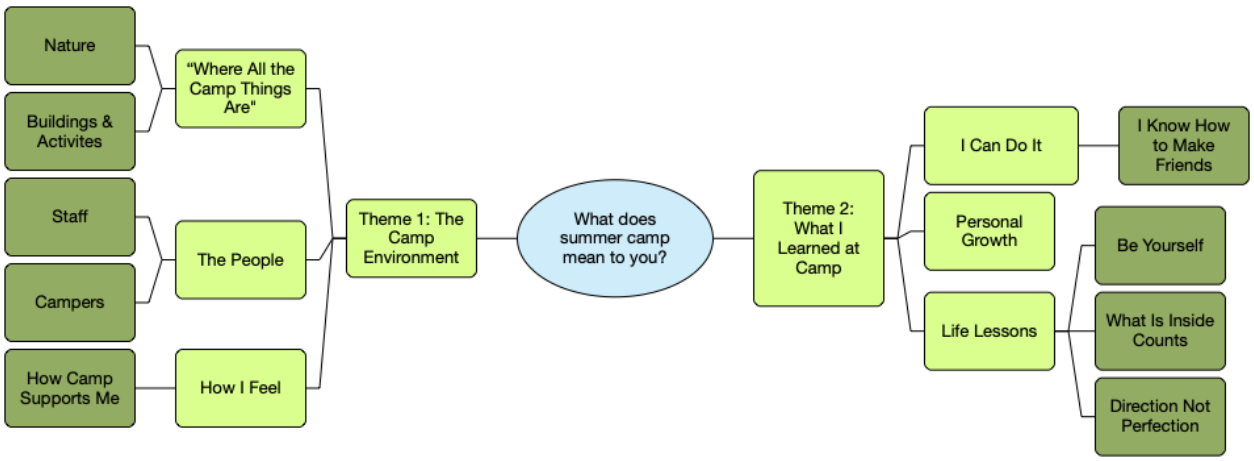

Figure 1. NVivo Software depiction of the themes covered in chapters 2 & 3.

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Chapter 2: Exploring the Summer Camp Environment with Adolescents with Neurobiological Disorders

Target Journal: Children, Youth & Environments

Introduction

Recreation and leisure opportunities are considered vital to the development of children. Recreational and leisure activities may be formal, which include organised activities such as sports teams or Girl Guides, or informal, which are less structured such as neighbourhood kids playing after school. Additionally, recreation has been acknowledged by the United Nations as a fundamental right for children as detailed in Article 23 and 31 of *Convention on the Rights of the Child* (1990). Activities include games, sports, arts, crafts, culture, hobbies, and socializing and should provide opportunity for individual development, and social integration (United Nations Human Rights Commission, 1990). For both children with disabilities and their typically developing peers, recreational and leisure activities are associated with increased physical and mental health, positive social outcomes, unique developmental experiences, and increased quality of life (Bean, Kendellen, & Forneris, 2016; Dahan-Oliel et al., 2012; King et al., 2003). Summer camps are a popular option for formal recreational opportunities for many youths. Similar to other recreational programs, summer camps have been reported to support youths' needs of autonomy, competence, and relatedness (Bean et al., 2016) as well as opportunities for skill building and independence (Pharr, 2018).

There are a variety of options for caregivers of youth with disabilities regarding the type of summer camp to which they can send their child. There are day camps, where a child is dropped off in the morning and picked up at the end of the day, or residential programs, known as sleepaway camp (Our Kids, 2014). At sleepaway camp, campers attend camp for typically a

minimum of one week but often up to eight. They leave home to sleep in a cabin with their peers, they are encouraged to make decisions about their own activities or the activities of a group, and they participate in new activities (Meltzer et al., 2018). For caregivers with a child with a disability, there is also the option of integrated or segregated programming. Youth with disabilities in Ontario, such as those with neurobiological disorders, have the right to participate fully including participation in recreational and leisure activities as stipulated by the Accessibility for Ontarians with Disabilities Act (Meilleur, 2006).

The term neurobiological disorder is an umbrella term that refers to a wide range of brain disorders that occur as a result of an interaction between an individual's biology and neurology including psychiatric disorders such as mood disorders and anxiety disorders, as well as childhood developmental disorders such as autism spectrum disorder and Tourette's syndrome (Buxbaum, 2013). Many neurobiological disorders affect motor skills, behaviour, mood, communication, learning, and/or social skills in varying degrees and combinations depending on the disorder and the individual (American Psychiatric Association, 2013; Dahan-Oliel et al., 2012). This project specifically uses the term neurobiological disorder, which is a medical term. This term was chosen as opposed to disability, which can be considered a legal or socially constructed term, because not all individuals with a neurobiological disorder consider themselves to have a disability. The main reason for this choice in language is that this project has taken a strengths-based approach and language around disability tends to focus on inability and deficits. As a result of their neurobiological disorder, many children and teens are excluded from what may be described as an inclusive program.

For youth with neurobiological disorders, social and institutional barriers to participation may prevent them from engaging in integrated programming. Social barriers include negative

attitudes or a lack of awareness from staff or peers in a given program, resulting in feelings of exclusion (Jones, 2003; Mulligan et al., 2012). Institutional barriers include policies requiring children with disabilities to have a 1:1 support worker ratio, a policy that increases the cost for the child and creates a financial burden for access to recreational programming (Shields & Synnot, 2016). Caregivers of children with neurobiological disorders are often already facing financial burden. An American study comparing family financial and employment impacts reported 39% of caregivers of a child with autism spectrum disorder (n=185), and 52% of those with both autism spectrum disorder and an intellectual disability (n=178) reported that their child's condition resulted in an excessive financial burden (Ouyang et al., 2014). For families in Canada, the financial burden comes from direct out-of-pocket costs for those items not fully covered by provincial health care plans such as prescription drugs and specialised equipment. There may be additional indirect financial burden from lost wages as result of increased child care needs (Plumb et al., 2015).

Following the civil rights movement in the mid 1900's for the rights of people with disabilities, many negative beliefs regarding disability-specific spaces arose, including the belief that such programs were stigmatizing and criticism that fundraising tactics capitalised on pity (D'Eloia & Price, 2018; Goodwin & Staples, 2005; Prince, 2009). As a result, the availability and popularity of integrated programs increased and disability-specific programs exclusively for youth with disabilities have faded into the margins. Disability-specific spaces have incredible value for young people and eliminate many of the barriers they face in integrated programming (Dahan-Oliel et al., 2012; Goodwin & Staples, 2005; Meltzer et al., 2018). Both integrated and specialised programs have benefits for youth with disabilities, though there are unique outcomes that occur when youth interact with peers with similar disorders or diagnoses (Goodwin &

Staples, 2005). Meltzer and colleagues (2018) surveyed 36 campers with severe illnesses before, after, and three months after attending a disease-specific summer camp in Colorado. Their results suggest that when campers with similar disorders or medical conditions attend camp together, they may experience increased feelings of security, hopefulness, and self-efficacy (Meltzer et al., 2018). There are additional outcomes for identity development and social acceptance as well as relaxation in a recreational setting, which may not come easily for many youth with disabilities (Dahan-Oliel et al., 2012; Goodwin & Staples, 2005). For many young people with a disability, peers of the same age in school or other activities may be judgemental and adults are often focused on the limitations of a disorder (Meltzer et al., 2018). The opportunity to connect with youth with similar life experiences has the potential for many positive implications for youth with neurobiological disorders.

There is extensive research concluding that summer recreation programming is valuable for children with disabilities. However, the research is largely lacking first-hand accounts from youth with neurobiological disorders. Rather, the vast majority of existing literature asks parents, guardians, or support workers for second-hand information regarding the experiences of children at camp (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012; Murphy & Verden, 2013; Walker et al., 2010). There has been minimal insight into the value of disability-specific spaces from the camper's point of view, specifically for youth with cognitive or neurobiological disorders. Additionally, there has been little exploration in the literature into the actual role of the camp environment (Clark & Nwokah, 2010). In fact, many of the studies that measured camp outcomes were pre- or post- reported, resulting in data that does not capture the nuances of daily camp experiences (Clark & Nwokah, 2010). As a result, the existing research may considerably underestimate the importance of the camp environment. In light of the limitations in the existing

literature, this project sought to answer the following research question: How do adolescents with neurobiological disorders at a disability-specific sleepaway camp in Ontario make meaning of their summer camp experiences? This study was exploratory in nature and aimed to engage youth with neurobiological disorders in research in order to represent their perspectives on attending a disability-specific summer program.

Methods

A qualitative photovoice methodology was used to engage youth with neurobiological disorders in an exploration of what attending a disability-specific summer camp means to the campers themselves. The study was undertaken over the course of summer 2018 with campers at Camp Neuro in Canada.

Photovoice

Photovoice was used to address the research question in a participatory way. Photovoice is a flexible and empowering methodology that can facilitate research with vulnerable populations and challenge the assumption that a population has a lack of knowledge (Wang & Burris, 1997). Photovoice research invites participants to use a camera to take photographs according to a prompt or research question. The photographs are then used as tools for discussion in an interview setting with the goal of exploring the values and issues of a community. Finally, photovoice also incorporates a social action component to reach decision-makers and to benefit the participants themselves (Wang & Burris, 1997).

Typically, the interview portion of the photovoice methodology is conducted in small or large group discussions. The purpose of the group discussions is to allow participants to reflect on the images they have produced (Wang & Burris, 1997). There are documented difficulties in engaging youth with neurobiological disorders in group talk and emotional therapies (Humphrey

& Lewis, 2008; Kaehne & O'Connell, 2010), and the challenges were determined to potentially impact the depth of perspectives shared by participants (Jurkowski, 2008). Additionally, group settings are often stressful for individuals with neurobiological disorders (Ha & Whittaker, 2016). The current research project used a one-on-one interview style instead, which aimed to increase the comfort of the adolescents and respect the diversity of social and language abilities of this population. The individual interviews were an adaptation made for the current photovoice project from the traditional process. The adaptation was made to benefit the unique participant population while maintaining the original purpose of group discussions as outlined by Wang and Burris (1997).

Literature suggests that photovoice is an effective methodology for engaging groups that are often underrepresented by academic research, such as young people with neurobiological disorders (Ha & Whittaker 2016). The methodology successfully provides insights into the lives of marginalised populations and can deliver results that inform decisions that affect the lives of these communities (Ha & Whittaker, 2016; Jurkowski, 2008). In a study of nine participants aged 10 to 17 in Vietnam, children with autism spectrum disorder took photographs of their day-to-day lives (Ha & Whittaker, 2016). The researchers described that the participants in their study enjoyed taking pictures of what they wanted, enjoyed sharing their photos, and that that they entertained themselves with the cameras (Ha & Whittaker, 2016). The success of Ha and Whittaker's study (2016) provided strong justification for the use of photovoice in the current study.

Camp Neuro

The current study was conducted at a sleepaway summer camp for children and teens with complex neurobiological disorders in Ontario. The camp, referred to by the pseudonym Camp

Neuro, runs four two-week sessions over the course of the summer for a total of 145 campers with two sessions for male campers and two for females. Campers are aged six to 17 and have a multitude of complex neurobiological disorders including autism spectrum disorder, fetal alcohol spectrum disorder, oppositional defiant disorder, attention deficit (hyperactivity) disorder, and Tourette's syndrome. Some campers have multiple diagnoses, which further complicates their health and behaviour through the complex interaction of comorbidities. Camp Neuro welcomes children and teens who require a higher level of support than those at similar recreational programs. As a result, it features a population of adolescents who are often excluded from integrated camps and even some disability-specific camps.

The population of campers at Camp Neuro is diverse. Campers are invited back each subsequent year until they reach the maximum age 17 years, establishing Camp Neuro as a stable and constant support system for families. Participants of this study have all attended camp for a minimum of two years and up to ten. Additionally, Camp Neuro provides extensive financial support to alleviate the cost barrier that exists for many families of youth with neurobiological disorders seeking appropriate supportive recreational programming. The philosophies and policies in place ensure a diversity of socio-economic status, gender expression, sexuality, race, and guardianship. This study site was selected primarily due to the researcher's existing working relationship for four years with the organization and her knowledge of the Camp Neuro program. It is important to note that at the time of data collection the researcher worked as a staff supervisor in the 13-and-under camper program and was not directly involved in the day-to-day camp activities in the teen program. A map is detailed in Figure 2 for the reader to familiarise themselves with the layout of Camp Neuro.

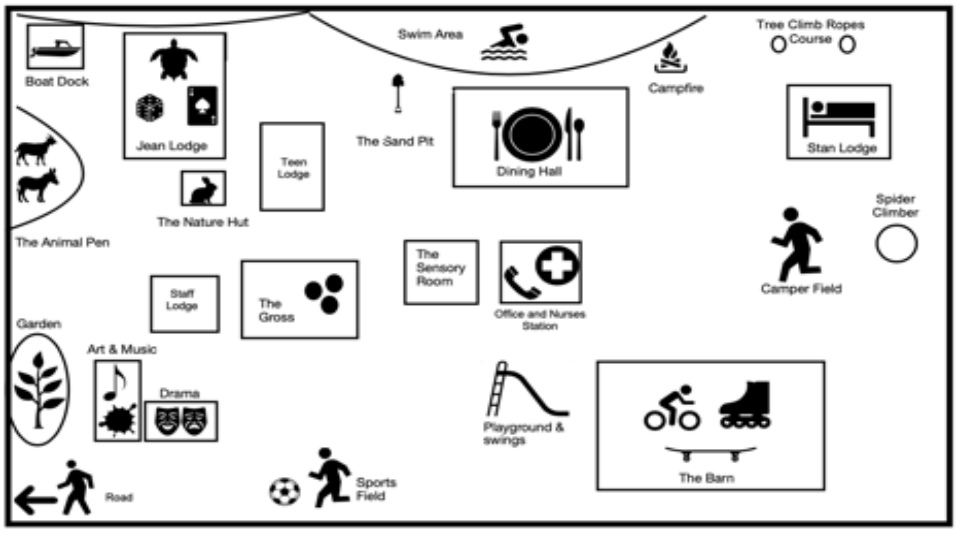

Figure 2. Map of Camp Neuro

Participant Recruitment

With approval from Laurentian University's research ethics board, an opportunistic sampling strategy was used to recruit participants. Eligible individuals included campers who were attending Camp Neuro's teen program in summer 2018, who were between the ages of 14 and 17, and who had a parent or guardian-reported neurobiological disorder, a qualification which is inherent to their attendance at this particular summer camp. Participants of all genders from the four sessions were invited to be included in the study.

Campers that qualified for the study according to the selection criteria were contacted by email by the camp administrator with an information letter and letter of consent at the beginning of June 2018. The participants in this study are minors. Therefore, informed consent was obtained from a parent or guardian, and informed assent was obtained from the adolescents themselves at the study site. Only campers with both parental consent and continuous assent were included in the research study.

Data Collection

Data collection began June 2018. This research project featured two interconnected phases with assent processes followed before each. Phase one involved all participants taking photographs of what Camp Neuro means to them. Participants were asked to take pictures that captured both things that they like about camp as well as things that they find challenging. For phase two, participants were invited to an individual interview to talk about their photos. Participants did not have to take part in phase two, though all participants were given the option. Twenty-three adolescents participated in phase one of the research by taking photographs at Camp Neuro and 13 also participated in phase two, the individual interview.

Phase one of the study began within the first three days of the teen's arrival to camp. An information session was provided to the staff who work directly with the adolescent campers to ensure that counselors supervising the photograph taking were aware of the process and the appropriate ways in which to support their campers. During an initial conversation, participants were introduced to the study including the steps associated with photovoice and what they would be asked to do. The rules of picture-taking were also outlined (e.g. no photographs of people, stay on camp property, protect personal safety). Each participant was given a printout that included the question "What does Camp Neuro mean to you?" and the rules. This introduction was conducted individually in order to accommodate participant's communications skills and needs.

Each evening, campers who are 14 and older choose their schedule for the next day from a list of optional activities. Photo-taking was included on this list and therefore participants had the flexibility to decide on which day and during which hour block they wanted to take their photos. At the start of that hour, participants signed out a digital camera from the camp office and took their photographs around camp. Participants had the option of signing up to use the

camera multiple times during the day or over multiple days. Once they had completed their picture taking, their photographs were uploaded to the researcher's secure computer in an individual file. A printed copy of their photographs was made for each participant if they so desired.

In the second week of camp, once they had taken their photographs and made their selections, participants were invited to sign up for an interview time if they expressed interest in phase two. Participants chose the day, time, and place for their individual conversational interview in the same way that they scheduled camera time. During the interview, participants were able to navigate through their photographs on the computer as they wanted in order to guide the conversation. Originally, it was intended that participants would select five photographs to discuss at their interview, however most participants wanted to discuss all of their photographs and so they were given freedom to decide which photographs they wanted to discuss and how many. The photographs taken by participants were used to guide the conversation about the meaning of camp, beginning with the open-ended question, "tell me about your pictures". Additional probes such as "why did you take this photo?", "how does this picture make you feel?", and "were there any photographs that you did not take that you wish you had?" were used depending on the participants' comfort and openness. Interviews ranged in length from 4.36 mins to 63.27 mins. Interviews were audio recorded and transcribed. At the end of the interview, participants were invited to select their own pseudonym to protect their identity.

Data Analysis

The data generated by this study was qualitative and included the photographs taken by the adolescents as well as the individual interviews. Inductive thematic analysis was used to analyze the qualitative data using Braun and Clarke's six step approach to analysis (2014). The

data analysis focused on understanding the meaning, purposes, and intentions of the participants (Smith, 2008). Analysis focused on obtaining a rich description of the data set in order to feature the perspectives of the participants (Braun & Clarke 2006). The audio recorded interviews were transcribed verbatim and de-identified. Both the photographs and transcripts were imported into QSR NVIVO®, a qualitative data management tool.

Following familiarization of all data including audio data, transcripts, and the accompanying photos, the interviews were coded according to a semantic focus. Because of the limited story-telling abilities of young people with neurobiological disorders and the spectrum of verbal communication skills, a content analysis of the photographs was used to supplement data from the conversational interviews (Ha & Whittaker, 2016). Photographs were then coded according to the pre-determined factors of focus and location, as described by Ha and Whittaker (2016; Bock, Isermann, & Knieper, 2011). All photographs were coded, regardless of a participant's engagement with phase two of the research study. Frequency analysis was used to consider what is presented in the entire group of images but was not concerned with statistical significance. Coding of visual data took place after coding the interviews, but both sets of data were considered in conjunction in order to establish, triangulate and verify themes (Ha & Whittaker, 2016). Data triangulation was achieved by the use of both visual data and interview transcripts for the development of themes and was used to promote the trustworthiness of the results of this study as well as to enhance the overall rigour (Creswell, 2007; Denzin & Lincoln, 2005). The process of developing themes was iterative. That is, the researcher engaged consistently with the transcripts, photographs, codes, and themes moving towards more specific coding and finalizing themes.

Demographic statistics including age, gender, and comorbid diagnoses were also collected for each participant from guardian consent forms. Gender demographics were used to compare the themes from male and female campers. Twenty-three teens took photographs of their camp as part of this study, and 13 subsequently participated in an individual interview. Of the total 23 participants, four participants identified as female and 19 identified as male. Participants took an average of 35 photographs with a range of four to 113 for a total of 809 photographs. Table 1 summarises the demographic information of the 13 participants who were interviewed.

Pseudonym (as chosen by the participant)	Gender	Diagnoses	Number of photos
Purple	F	Anxiety	5
Craig	M	FASD, ADHD	14
Dumbledore	M	ADHD, Depression	4
John Casey	M	ADHD	18
Niminodin	M	FASD, ADHD	109
Pokémon	M	ADHD, Developmental delay	5
Cream	F	ASD	13
Toppy	F	ASD	20
Dragon	M	ASD	36
Kim	M	ASD	27
Lionel	M	ASD	11
Nick	M	ASD, ADD, Tourette's Syndrome	32
The Counsellor	M	ASD, ADHD	25

Table 1: Demographics of interviewed participants.

Note. FASD- fetal alcohol spectrum disorder, AD(H)D- attention deficit (hyperactivity) disorder, ASD- autism spectrum disorder.

The Camp Environment from the Perspectives of the Campers

Through inductive thematic analysis of the interview transcripts as well as content analysis of the photographs, the camp environment was determined to hold significant meaning to the participants. The camp environment was subdivided into three dominant themes: *Where All the Camp Things Happen, The People*, and *How I Feel*, which were broken down into further sub-themes. The titles of two of the three themes, *"Where all the camp things happen"* and *The People,* were direct quotes taken from participant interviews.

"Where all the camp things happen" (John Casey)

Many participants described the locations around camp that were meaningful to them. John Casey specifically talked about the waterfront area at Camp Neuro where there is a firepit just in front of the lake. He explained that to him, it is this spot with a campfire and the lake that really feels like summer camp and where, as he said, "all the camp things happen". The participants discussed the meaning of the physical space of Camp Neuro in terms of both the outdoors and the built environment, including activity areas.

Nature

Twelve participants discussed the meaning of nature and being outdoors at summer camp. Nature, including plants, the lake, and rocks, was the focus of 134 photos. In the interview phase, most participants expressed positive feelings towards spending time outside. Additionally, both male and females discussed nature at a similar frequency in their interviews according to a frequency analysis (0.21% and 0.24% respectively). Two participants specifically brought up the benefit of taking a two-week break from technology and electronics. Nick talked about what being outside means to him:

> You got the playground, you got- you're basically in the sun so it makes you like, instead of being in your room playing video games and being always like in your room, you'll come home hopefully and be like you know what, I'm going to go outside once in a while.

Nick, a teen with three separate neurobiological disorders, has a complex home life. Throughout his interview, he discussed frustrations with home and school and often talked about nature in the context of an escape from the city, the pollution, and the people there.

Many participants also specifically photographed the lake at Camp Neuro (Figure 3). Purple said that the lake was one of the things she was most excited about when she first got to camp, and Kim explained that what he likes about the lake is how relaxed he feels when he is swimming. For many, the lake is viewed as an integral part of the camp landscape that is also connected with the opportunity for water activities and quality social time with other campers and staff.

Figure 3. Participant 2's photograph of the lake.

Other participants talked about some of their frustrations with having to spend so much of their time outside. The Counsellor said that nature is "where mosquitoes lives and they bite you", while Dragon specified his frustration at "camp's inability to contain them [the mosquitos]" (Figure 4, cropped for clarity).

Figure 4. Dragon's photo: 'mosquitos are a very strong definition of what, that define to be at Camp Neuro'.

Buildings & Activities

In addition to the natural environment, participants also discussed the meaning of the buildings at Camp Neuro. Many of the participants discussed the recent renovations, including a new Teen Building where they all stayed during their time at camp. Niminodin talked about coming back to camp to a new building:

> I love the teen lodge. I love the new teen lodge. Not only does it have a bathroom upstairs but it's a completely new building right? Not like the old wooden one that was falling apart. I mean, I wouldn't have had a problem coming back to it.

Dragon was similarly excited about the new building:

> Excited that we have a new teen lodge. This is what should have happened a long time ago. This is what I can finally. I say oh my god, ya [laughing]. That's why I took a picture of that.

Other buildings around camp were discussed by participants as holding specific meaning. A number of participants talked about the dining hall, specifically the good food and knowledge about nutrition that they receive there. There were a number of photographs of the large food group posters and a painted wooden food rainbow showing all the different colours of food that are hanging in the dining hall where all campers eat their meals. The nature hut and adjoining animal pen were also popular. The nature hut is a building where smaller animals are housed such as a tortoise, guinea pigs and various birds, and is attached to the large animal pen where an alpaca, a donkey, goats, and sheep live. Of the pictures with identifiable locations, the greatest number (91) were taken in the nature hut.

The built environment at Camp Neuro also encompasses activity spaces. The most popular were: the boat and boat dock; the barn, which holds the sports equipment including basket-ball nets and a collection of bicycles; and the climbing equipment including a high ropes course and ‘spider climber’. When talking about activity areas, participants talked about the fun that they have at camp as well as new skills they have learned (Figure 5). Eleven participants took photographs of the drama room and three participants talked about their picture of the drama room in the context of learning social skills. The youngest campers, aged six to nine typically, have an hour called ‘social skills’ every morning in the drama room where they sing songs and play games in order to learn how to make and keep friends. The participants who talked about the drama room were reflecting back on their early years at camp. Niminodin said “a lot of my patience and companionship has been built from that [social skills]”.

Figure 5. Toppy's photo: "Tree climb, again another favourite... I really like climbing and trying to get to the top."

The People

Purple summed up her experience at Camp Neuro by saying that “camp kinda gave me new opportunities to make friends and form relationships with other people”. The people comprising the social environment of Camp Neuro are an incredibly meaningful aspect of camp, discussed by twelve of the thirteen interviewed participants. A frequency analysis of the interview transcripts revealed that female participants discussed people more frequently than male participants (1.02% and 0.55% respectively). With regards to photographs two out of the four female participants took photographs where unidentifiable people were the focus and only

four of the 19 male participants did the same. Participants talked about both campers and staff, with both groups contributing significantly to the camp's social environment.

Staff

Many of the participants discussed the support and comfort that they receive from the staff at Camp Neuro. Nick specifically talked about his relationship with a member of the maintenance team, Steven, and how much he's learned from him:

> "Ya, Steven is like a really good guy. I hope he listens to this and says like yo. I love you too. Steven is awesome, he's just... He can teach you a lot of valuable stuff and he's patient and he's not like oh my god, oh my god I guess like yelling and stuff. He's patient, he'll show you how to do it then you could take that into the world and be like, I know how to do this."

Participants largely expressed positive feelings toward the Camp Neuro staff. Cream said that the staff "treat you special" when you are at camp and Kim said that "some counsellors have really helped me and comfort me". Many told stories of support or talked about specific staff with whom they have a close relationship.

Dragon, a teen with an autism spectrum diagnosis and strong intellectual skills, was the only participant to talk about his frustrations with the "incompetent staff this year". He referenced many stories of staff errors or miscommunication that affected his schedule resulting in frustration for both parties. He also mentioned strong distaste for one of the common lines used by staff at Camp Neuro, which is: 'That is not an option. Which is what staff enjoy saying, which is what staff have a tendency to say. Which I really hate, yet they keep insisting on saying it… That's not an option right now. And you've made your choice. It's like, are you trying to provoke me?"

Campers

The nine participants who talked about other campers primarily discussed them in the context of friendship. Most referenced that the social environment of Camp Neuro made it easier to make friends and they valued the friendships made at camp (Figure 6). Kim talked generally about friendships at camp, saying “I do know for a fact that like Camp Neuro, you do make friends here. I've seen that happen a couple of times”.

Figure 6. Photograph by participant 6.

Participants also discussed some of their challenges with friends. One participant explained that it is difficult for her to socialise and make friends because of her autism. While Purple said that her “friends at camp understand [her] more”, she also identified the changing participants each summer as her main challenge at Camp Neuro:

> Because every year it changes and especially because I had to come during a different session this year I'm not going to be with my other friends, and that's- that was kind of tough in the beginning but like, I'm always going to see them again so like, the new possibilities is like unexpected relationships with my peers and my cabin.

Only one participant also talked about challenges of spending two weeks with campers he was not friends with. Nick described feeling afraid around some campers because he "didn't, like, understand these medical problems".

How I Feel

Participants also discussed the meaning of the emotional climate at Camp Neuro and how they feel during their two-week sessions at camp. The emotional climate is a concept that represents the emotional relationships among members of a community and reflects how most members feel in their given situation, as experienced by insiders of said community, in this case the research participants at Camp Neuro (Rivera, 1992). Overall, through the interviews, participants described an emotional climate of comfort, with three participants using that term exactly and eight others using synonyms such as welcoming and relaxing. Nick described his overall feeling of camp as "just, you feel comfortable wherever you go".

Seven participants used the word happy to describe their experience at camp. When asked how camp makes him feel, Kim said "I guess mostly happy". Nick concluded his interview saying that "camp is like, you come to be happy". Two other participants similarly described the overall feeling of Camp Neuro as welcoming.

Camp Supports Me

While accommodation was not discussed by many of the participants, it was an important aspect of the social environment for some. Only six of the participants made reference to their disorders or the fact that they were attending a disability-specific summer camp. When it was discussed, however, it was clear that the support and accommodation of a disability-specific summer camp made a significant impact on the participants' experiences at camp. Dragon talked about different parts of his OCD and when discussing a photograph that he took of the nurse's station washroom, said that the fact that Camp Neuro "accommodates [his] need for various reasons and including privacy is something [he] will value for, for a significant amount of time" (Figure 7). Other teens discussed behavioural challenges or learning difficulties that were addressed and supported at Camp Neuro. Those who discussed their diagnoses also acknowledged how far they have come in their years at camp and the benefit of being supported.

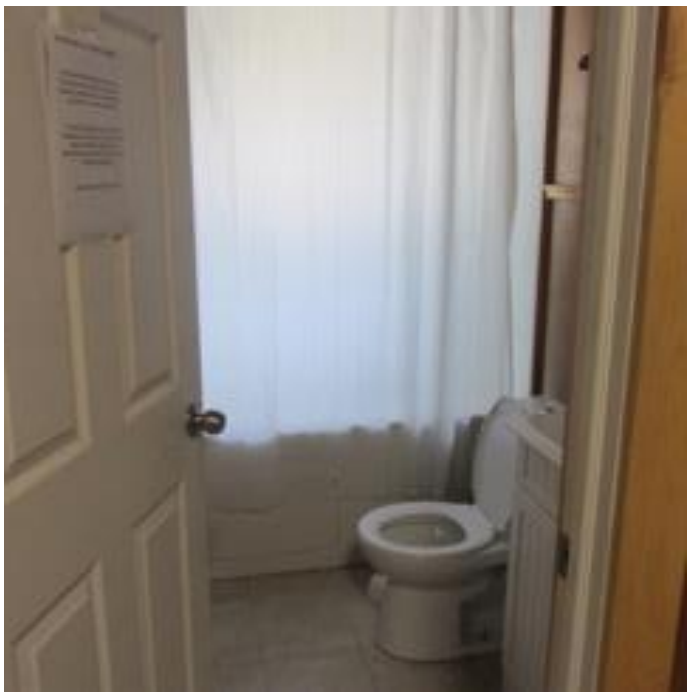

Figure 7. Dragon's photo: "this picture symbolizes my need for various personal needs including privacy".

Niminodin, for example, described himself as “not an easy learner” but explained that camp showed him “there’s always a way to teach someone the way they need to be taught”.

Discussion

There is extensive research from the perspective of caregivers and staff to suggest that summer recreational opportunities are beneficial for youth with neurobiological disorders (Dahan-Oliel et al., 2012; Goodwin & Staples, 2005). This study contributes to this body of literature by providing the perspectives of the campers themselves. Specifically, the themes determined by thematic analysis suggest that the physical, social and emotional environments of exclusive disability-specific spaces are meaningful to adolescent campers with neurobiological disorders.

Much of what the participants discussed in their interviews as meaningful about Camp Neuro are aspects that would be found at many typical summer camps. Activity areas, time spent in nature, supportive staff and the opportunity to make friends are all commonly found across youth-centered leisure programming (Pharr, 2018). Few participants discussed their neurobiological disorders in much detail or focused on the fact that their summer camp is exclusively for youth with neurobiological disorders, though the vast majority would be aware of this fact. The lack of disability-specific themes is relatively unsurprising given that Camp Neuro is not a therapeutic program. Rather it is a recreational-focused leisure program that provides an environment for youth with complex neurobiological disorders to simply have fun with support for their various needs and, like other disability-specific summer camp programs, provide the youth access to activities that they previously could not engage in. Meltzer and colleagues (2018) found that the benefits of disease-specific summer camps are that these specialised programs allowed children to experience activities that had “previously been off-limits due to their illness”

(p. 278). For youth with neurobiological disorders, it is often not their disorder that inherently makes activities off limits, but rather their individual needs and behavioural challenges. While it was not discussed in the interviews, many of the campers at Camp Neuro had been removed from various other recreational programs due to challenging behaviours or high support needs. Participants in the current study described enjoying typical summer camp activities such as the high ropes course or swimming in the lake. Camp Neuro provides them with a normative camp experience with additional support to help them to be successful. Their discussions of the traditional camp activities suggest that participation in a specialised program may allow youth with neurobiological disorders to relax and play in the same ways as youth at mainstream summer camps when given the supports and accommodation they need. Further, it supports the notion that it is less important whether a program is integrated versus disability-specific, what matters is the ability for a camper to participate meaningfully with individual, appropriate support (Dahan-Oliel et al., 2012).

For school aged children and into adolescence, the opportunity to participate in social play is important and the social environment can either facilitate or hinder the extent of that participation (World Health Organization, 2007). The participants at Camp Neuro emphasized the importance of friendship from their perspective and discussed that a comfortable and accommodating environment was important to them. They were also given the opportunity to learn social skills at a young and influential age and the understanding emotional climate at Camp Neuro likely facilitated friend-making. When campers with challenging behaviours are included and welcomed into a recreational program with support, it is clear they have the capacity to be incredibly successful and have positive emotions associated with the experience. The inclusive program model has the potential to positively engage these youth with

neurobiological disorders, but currently only specialised programs have the reduced environmental and institutional barriers as well as the necessary supports to accommodate campers with complex needs. The words of the youth show how important the different supports they receive at camp are and the extent to which they impact their experiences. These same supports may not be available at integrated summer camp programs. The high ratio of staff to campers at Camp Neuro, as well as the tendency for campers to return annually creates an environment of support that is prepared to meet the needs of each individual camper. At integrated recreational programs, the needs of children with neurobiological disorders must be balanced with the goals of the program and staff must provide attention to a larger group of children with varying needs.

The use of photovoice with adolescents with neurobiological disorders was a valuable methodology for engaging the teens at Camp Neuro, particularly those with limited verbal communication skills. By using photovoice in this research project, adolescents with neurobiological disorders were able to express the value of their camp community and discuss both what they liked and what they struggle with (Wang & Burris, 1997). Many participants took photographs enthusiastically and asked if they could use cameras for various other projects as well or take additional photographs around camp. Other participants discussed their own motivations for wanting to take part in this research project. Kim, who had been dealing with some intense homesickness over his session, talked about his discussion with his mother about participating in this research project. He had wanted to participate because he was taking a photography course in school in the fall, but his mom had suggested that “she thought it was great to express [his] emotions about Camp Neuro”. When asked about how he felt about it after taking the photographs and participating in the interview, Kim said that “it doesn't necessarily

make the challenge like any easy like that much easier, but it does feel great to talk to someone else about it". Kim's feelings about his participation in this study provided support for one of the intended outcomes, which was to provide participants with the opportunity to explore their feelings about Camp Neuro and their summer camp experiences.

The completion of the main photovoice phases at Camp Neuro, during each participant's session at summer camp was also crucial to the success of this project. As previously discussed, much of the existing summer camp research is conducted outside of summer camp itself (Clark & Nwokah, 2010). It is well documented that individuals with neurobiological disorders struggle with episodic thinking; that is, they often have a reduced ability to recall past events as well as imagine future ones (Bowler, Gardiner, & Gaigg, 2007; Crane & Goddard, 2008; Terrett et al., 2013). As a result, asking participants about what camp means to them while at camp likely yielded much more rich and insightful results than if this study had elected to ask them to reflect on camp after it had ended.

Photovoice as a methodology also has a strong social action element (Wang & Burris, 1997). The use of photovoice to engage youth with neurobiological disorders in research opens the door to their social reality (Jurkowski, 2008). The results should therefore be used to benefit the participants themselves and inform real societal change. The results from this research can be used to develop more meaningful and accessible recreational programs for children and teens with complex neurobiological disorders. In order to work towards social action for this population, an exhibit of the participant's photographs will be held in partnership with Camp Neuro. The exhibit will also feature quotes from the youths. A member-checking event and exhibit brainstorming session will be conducted in small groups or individually with research participants. Decision makers at Camp Neuro and directors from similar programs will be invited

in order to understand the perspectives of their campers and work towards more inclusive programming for the benefit of youth with neurobiological disorders. The social action component of photovoice bridges the results of the research into benefit for the participants themselves.

There were some challenges associated with the interview phase of photovoice with teens with neurobiological disorders. Many teens struggle with verbal communication and, specifically, with identifying and discussing their emotions. Dragon, in particular, had difficulty with the on-the-spot nature of the individual interviews and figuring out which words truly captured his thoughts and feelings. At numerous points throughout his interview, Dragon made use of a thesaurus to find the perfect word for his, as he put it, "inconceivable thoughts". Toppy, Nick and John Casey struggled similarly, all expressing that there was something that they liked about camp, they just did not know what or they were not sure how to put their thoughts into words. Using the photographs provided an essential tool to bridging these communication challenges. The pictures that participants took started the discussion and gave them something to begin talking about. By beginning with concrete questions such as "what is this photo of?" or "where did you take this picture?", the teens were able to get more comfortable with the interview process and many eased into talking about their more abstract thoughts and feelings about camp. While the interviews did present a challenge, having the photographs helped in the research process.

Ten participants engaged exclusively in phase one of the research project. While their photographs were valuable contributions to the project, the research is lacking their contextualization of their photos. Of the participants who are effectively non-verbal, none participated in the interviews. High-needs campers have more structured days at Camp Neuro

and rely more heavily on consistency in their days. As a result, high-needs participants were less likely to take part in an individual interview because it posed a greater disruption to their day in comparison to taking photographs. High-needs individuals are therefore underrepresented in the contextualising portion of the study.

This study focused on a small group of adolescents in Ontario at a specific recreational program. The participants represent a population of high-needs individuals with limited options for support. The results of this study, therefore, are not generalizable to the larger population of youth with neurobiological disorders. Additionally, the researcher was not involved in the photo-taking phase of the research. While there are benefits with this approach, it does mean that it cannot be guaranteed that photo-taking was not influenced by the staff supporting the youth on a daily basis. However, staff did receive training on the appropriate ways to support campers in taking the photographs before the project began.

The results of this study support summer camp as a supportive and meaningful environment for adolescents with neurobiological disorders. The participants in this research provided rich descriptions of the activities that they had enjoyed at Camp Neuro and the social connection that they had experienced. These narratives are valuable when considering how to increase the accessibility of recreational services for youth with neurobiological disorders. This study may be used to inform recreational programming, both integrated and disability-specific, to develop physical, social, and emotional environments that accommodate the needs for this population and allow for fun summer camp experiences.

Conclusion

Youth with neurobiological disorders are a diverse group, often with complicated and diverse needs. A specialised recreational program provides these adolescents with the necessary

supports in order to participate fully and successfully in summer camp. Photovoice provided a valuable methodology to capture the unique perspectives of the participants at Camp Neuro. These adolescents identified the meaning of the physical, social and emotional environments of summer camp and the value of the supports provided to them, which enhanced their participation and experiences.

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Chapter 3: “What matters is what you look like on the inside”: What adolescents with neurobiological disorders have learned at sleepaway summer camp

Target Journal: Disability and Society

Introduction

Neurobiological disorders are a complex set of diagnoses that may result in a variety of social, emotional, and behavioural challenges (American Psychiatric Association, 2013; Buxbaum, 2013). Respite services provide a break for caregivers from the physical and emotional demands of caring for a child with a neurobiological disorder. However, there is limited research on the experiences of respite service users and the vast majority of respite related research has focused on the experiences of parents and staff (MacDonald & Callery, 2004). There has been very little research that has featured the perspectives of the children with neurobiological disorders who receive respite care. The lack of children’s perspectives may be the result of societal assumptions of the verbal and communication limitations of youth with neurobiological disorders and their assumed inability to participate meaningfully in research. During the summer months, summer camp can be considered a form of respite services for families with a child with neurobiological disorders. This study employed photovoice methods to explore what summer camp means from the perspective of campers themselves and to understand the value and challenges of specialised recreational programming to teens with neurobiological disorders. Firsthand insight into the experiences of youth with neurobiological disorders at summer camp is incredibly valuable for understanding what about recreational programs is important to their campers and how to better serve this population.

Disability perspectives

Neurobiological disorders are a group of brain disorders that arise as a result of complex interactions between human neurology and biology. The umbrella term encompasses both psychiatric disorders, including mood disorders like anxiety, and childhood developmental disorders such as autism spectrum disorder and fetal alcohol spectrum disorder (Buxbaum, 2013). Neurobiological disorders may affect an individual's motor skills, communication skills, social skills, mood regulation, and behaviour in a range of ways and intensities all of which influence the level of care they need (American Psychiatric Association, 2013). According to a 2012-2013 overview by the Ontario Ministry of Education, 9.18% of the enrolled school population was identified as "exceptional" (Ontario Ministry of Education, 2014). Exceptionalities include behavioural challenges, intellectual conditions, communication disorders, and physical disabilities. Over 42% of students with exceptionalities were identified as having a learning disability while 9% were diagnosed with autism spectrum disorder and 5% had behavioural challenges (Ontario Ministry of Education, 2014). Additionally, more than 5% have multiple exceptionalities (Ontario Ministry of Education, 2014). Ontario, and Canada as a whole, does not use neurobiological disorders as a category of disability, so the statistics on the prevalence of the entire group of diagnoses is not reported. For comparison, however, England estimated their national prevalence of neurobiological disorders to be between 3 and 4% among children aged 0 to 18 years old (Blackburn et al., 2012). It can be estimated that in Canada, the percentage of children with neurobiological disorders is a significant proportion of the total children with identified exceptionalities.

Society has a profound effect on the treatment, recognition, and respect of individuals with neurobiological disorders. The social model of disability evolved in the 1970's as a social

justice movement by individuals with disabilities in an effort to reclaim the narrative from medical professionals (Hiranandani, 2005). The movement was further developed by activists and researchers in the later 20th century in an effort to reframe societal views of disability (Oliver, 2013). Traditionally, under the medical model of disability, professionals dominated the conversation regarding the lives of those with disabilities while individuals with disabilities were marginalised and their perspectives were not considered at all in decisions that affected their lives (Hosking, 2008; Shakespeare, 2016).

The social model of disability positions disability as a social construct that is the result of systems of oppression (Hiranandani, 2005; Oliver, 2013). Proponents of the social model positioned impairment and disability as distinctly separate (Anastasiou & Kauffman, 2013). They defined impairment as referring to the functional limitations within an individual, whereas disability refers to the loss of opportunities to participate in a community as a result of physical or social barriers (Anastasiou & Kauffman, 2013; Barnes, 1991). The social model of disability also advocated to feature the voices of individuals with disabilities in decision making. In discussions regarding factors that affect the lives of people with disabilities, consultation with these groups became recognised as not only respectful, but crucial. Yet, frequently the opinions and experiences of individuals with behavioural and cognitive differences are still marginalised within society (Jurkowski, 2008).

Critical disability theory evolved from the principle of the social model of disability that states ableism is a social oppression that contributes to the disadvantage of individuals with disabilities (Abberley, 1987; Hosking, 2008). Ableism refers to the ways in which society defines different abilities as disabilities and results in discrimination against individuals with physical or cognitive differences (Harpur, 2012). Critical disability theory worked to challenge

this power dynamic that privileges typically developing and able-bodied individuals (Hiranandani, 2005; Hosking, 2008). While neurobiological disorders are included in critical disability theory, the predominant focus has been on physical or visible impairments (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). While the exact reason for this marginalisation is unclear, there are a number of possible explanations. Neurobiological disorders tend to be invisible impairments that lack unifying physical identifiers. The disorders originate in an individual's brain and are therefore highly variable. As a result, few universal facts about symptoms and manifestation can be determined (Anastasiou & Kauffman, 2013). Many neurobiological disorders are spectrum disorders, meaning there is a wide range of severity (American Psychiatric Association, 2013; Bagatell, 2010). Additionally, because impairment as a result of neurobiological disorders is primarily in an individual's brain, the identification of oppressive physical or social barriers is far more subjective and therefore more difficult to apply to critical disability theory (Anastasiou & Kauffman, 2013). While critical disability theory aims to dismantle systems of oppression, this goal is almost impossible when considering cognitive and intellectual disabilities with such a spectrum of challenges (Shakespeare, 2016). Marginalisation may also be the result of less advocacy from individuals with neurobiological disorders. Traditionally, there has been limited insight into the lives of individuals with neurobiological disorders with social, cognitive, and communication deficits (Anastasiou & Kauffman, 2013).

With all of these limitations in applying critical disability theory to neurobiological disorders, it is clear that a more individualised approach to advocacy is needed. For individuals with neurobiological disorders, it is necessary to acknowledge that each person has unique needs that require accommodation as opposed to an approach that removes universal barriers

(Anastasiou & Kauffman, 2013). Additionally, the social model of disability and critical disability theory may underestimate the intrinsic limitations of a neurobiological disorder. A Canadian study of adolescents with autism spectrum disorder (*n*=250) reported that 51% of the participants demonstrated self-injurious behaviours over the lifetime (Duerden et al., 2012). Self-injury may present as hitting the self with a body part or against an object or biting themselves. Other adolescents may scratch their skin or pull their hair. These dangerous behaviours have a spectrum of effects from minor pain infliction to permanent injury. To focus solely on the social construction of disability is to ignore the harmful symptoms of many neurobiological disorders.

Individuals with neurobiological disorders have adopted the slogan "nothing about us without us" that was popularised by the Disability Rights Movement (Bagatell, 2010). Activists associated with the movement advocate for the rights of individuals with disabilities to determine policies that affect their lives and allows them to represent their own needs (Bagatell, 2010). Again, while the initial movement was started by individuals with physical impairments and neurobiological disorders were not included at first, in recent years there has been an increase is self-advocacy from the autism spectrum disorder community in particular (Bagatell, 2010). The lag can be explained by the dramatic rise in technology and the internet explosion in recent decades, which provided many individuals with neurobiological disorders with options for assistive communication (Bagatell, 2010). "Nothing about us without us" also addresses many of the limitations associated with critical disability theory because it originated with members of the disability rights community. With regards to neurobiological disorders, in particular autism spectrum disorder, the movement has also included a push to recognise diversity in human cognition as difference rather than disease (Bagatell, 2010). As such, this research uses the term

neurobiological disorders rather than neurobiological disabilities in an effort to avoid imposing social constructions of impairment on the participants.

People with neurobiological disorders in research

People with neurobiological disorders have few opportunities to actively participate in research and frequently they have been employed as research subjects as opposed to participants (Jurkowski, 2008). Research subjects are traditionally passively involved in research and are individuals on whom experiments or tests are conducted. Alternatively, research participants are actively engaged in the research process (Corrigan & Tutton, 2006). Additionally, health research in North America and Europe has frequently focused on the tragedy of having a child with special needs (Goodley & Tregaskis, 2006). In research studies exploring the lives of youth with neurobiological disorders, the focus has remained on the perspectives of the decision makers; parents, caregivers, staff, and medical professionals (Jones, 2003; Schleien, Miller, Walton, & Pruett, 2014; Whitmore, 2014). Arts-based research such as photovoice provides researchers with the opportunity to achieve a richer understanding of the lives of individuals with neurobiological disorders (Jurkowski, 2008).

With the rise of critical disability theory and disability activism, individuals with neurobiological disorders were able to challenge traditionally oppressive methods that do not include their perspectives in research (Goodley & Tregaskis, 2006; Jurkowski, 2008). Additionally, disability activism moves to challenging societal views that assume individuals with neurobiological disorders do not have the capacity or the knowledge to contribute to research (Jurkowski, 2008). Neurobiological disorders may affect learning abilities or executive functioning as well as verbal and written communication (American Psychiatric Association, 2013; Buxbaum, 2013), many of the aspects that traditionally society uses to determine a

person's intelligence. Traditional methods of determining knowledge and conducting research may not accurately reflect the true knowledge of individuals with neurobiological disorders and may discount the value of their subjective experiences (Jurkowski & Paul-Ward, 2007).

Participatory research has been identified as an appropriate method for engaging individuals with neurobiological disorders or cognitive impairments (Jurkowski, 2008). Participatory methods strike a balance between the needs of the researcher and the needs of the participants by incorporating an action component to address the problems addressed by the research (Jurkowski, 2008; Wang & Burris, 1997). Photovoice is an example of a participatory method that has been successful in engaging individuals and youth with neurobiological disorders in research (see Ha & Whittaker, 2016; Jurkowski & Paul-Ward, 2007; Povee, Bishop, & Roberts, 2014; Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Photovoice invites participants to take photographs reflecting a research theme (Wang & Burris, 1997). Participants are then involved in small or large group discussions to interpret the photographs and develop a narrative addressing community concerns, social issues, or public health problems as relevant to the project (Wang & Burris, 1997)

Photovoice allows for diversity in cognitive skills as it does not rely on a participant's ability to read or write. Additionally, the flexibility of the method allows for a strengths-based approach to explore not only the challenges of a given topic, but also what works for the community (Jurkowski, 2008). Photovoice, as a participatory method, challenges traditional power dynamics in research and gives individuals with neurobiological disorders control throughout the process (Povee et al., 2014). While there has been an increase in engaging individuals with neurobiological disorders in research, the focus has largely been on the methodology as opposed to the results (Ha & Whittaker, 2016; Jurkowski & Paul-Ward, 2007;

Teti et al., 2016). Photovoice research with individuals with neurobiological disorders often detail the general value and challenges of using the methodology with this population rather than exploring a research question regarding a specific phenomenon or experience. These publications are informative but there remains a lack of information on the experiences and daily lives of individuals with neurobiological disorders. For many youth with neurobiological disorders and their families, respite care services represent one of the essential needs in their daily lives.

Respite care services

The demands of care of an individual with neurobiological disorders fall first and foremost to immediate caregivers, including parents and guardians. Respite care provides a reprieve for caregivers from the emotional and physical care activities for an individual with complex needs (Autism Ontario, 2018). Parents have described caring for a child with high needs as a stressful experience. Respite provides assistance to many of these families and the availability of respite care services is correlated with decreased levels of stress for caregivers (Whitmore, 2016; Whitmore & Snethen, 2018). Respite may be home-based, whereby a respite worker comes to the caregiver's home to care for the individual with a disorder, or residential where the individual comes to an alternate setting to receive care. Both provide parents, guardians and other members of the household with a break from the responsibilities of caregiving, while also providing the individual with a neurobiological disorder with recreational opportunities and exposure to new social relationships (Whitmore & Snethen, 2018).

Studies exploring the accessibility, effectiveness, and appropriateness of respite among caregivers are largely inconclusive. A Canadian study of mothers with children with intellectual disabilities who had also experienced a recent mental health or behavioural crisis (n=40) concluded that while barriers to respite exist, the majority of caregivers who needed respite and

sought out services were able to receive them (Weiss & Lunsky, 2010). Alternatively, a Calgary study that interviewed caregivers of individuals with both autism spectrum disorder and aggression (*n*=9) reported an overall inability to access and/or maintain respite care (Hodgetts et al., 2013). The difference between these two studies' findings suggest that more extreme externalized behaviours such as aggression may decrease the likelihood of obtaining and maintaining respite services.

For those who are successful in accessing respite services there are still many challenges. Parents have commented on the many requirements that must be satisfied prior to accessing care, comparing the experience to 'jumping through hoops' (Doig, McLennan, & Urichuk, 2009). There are complicated systems managing funding and respite providers that may or may not be integrated, leaving parents to navigate a confusing system alone (Doig et al., 2009). Additionally, caregivers have suggested that the most important part of respite care is flexibility based on the family's needs (Doig et al., 2009; Pollock et al., 2001) but that many of the systems in place providing respite care do not allow for that level of choice. There are also limitations with regards to services, funding, and providers (Doig et al., 2009) that limit the quantity and quality of respite that a family can receive (Dymond, Gilson, & Myran, 2007). Furthermore, most respite services act primarily as service coordinators and do not necessarily train individuals to work effectively with youth with neurobiological disorders (Dymond et al., 2007), which puts significantly more burden on caregivers to train front-line respite providers.

In the summer months, sleepaway summer camps provide an option for residential respite care. Specialised, disability-specific summer camps provide recreational opportunities for youth with specific disabilities that provide caregivers with an extended break. While inclusive recreational programs exist, where youth with neurobiological disorders can participate

alongside typically developing peers, barriers may prevent integrated programming from being a viable option. For example, staff at inclusive programs may lack knowledge about neurobiological disorders and therefore, might be unwilling or unable to provide necessary support to address individual camper's needs (Jones, 2003; Schleien et al., 2014; Shields & Synnot, 2016). Parents have described overnight respite as providing the most significant break from caregiving (MacDonald & Callery, 2004). In a UK study on the meaning of respite, one parent said that when his daughter is away overnight, "it isn't for Hannah, it's to give us a break from Hannah" (MacDonald & Callery, 2004, p. 283). While it is clear that respite is necessary for caregivers, little is known about what campers themselves think about their time in recreational respite programs. Youth with neurobiological disorders have a fundamental right to express their opinions on the programs and services they receive (The United Nations, 2006, art. 21). Engaging youth with neurobiological disorders in research will provide insight into their perspectives on respite programs and can possibly assist with developing programs to address their expressed needs.

Methods

This study set out to answer a research question exploring how adolescents with neurobiological disorders make meaning of their summer camp experiences at a specialised sleepaway camp in Ontario, Canada, herein referred to as Camp Neuro. A qualitative photovoice methodology (Wang & Burris, 1997) was used to engage the teenage participants and approach the research in a participant-directed way.

Photovoice

Photovoice is a qualitative methodology that was originally used for community engagement in health research (Wang & Burris, 1997). The structure of photovoice involves

inviting community members to take photographs that capture their responses to a prompt or research question. The photographs are then used to facilitate a discussion about their experiences. Photovoice also typically includes a social action component that aims to benefit the lives of the participants themselves (Wang & Burris, 1997).

The existing literature suggests modifications to the traditional photovoice model in order to increase the comfort and engagement of individuals with intellectual disabilities, young children, and individuals with autism spectrum disorder in the research process (Ha & Whittaker, 2016; Jurkowski, 2008; Lal, Jarus, & Suto, 2012). A number of these suggested modifications were implemented for this project. First, individual conversational interviews were used in lieu of traditional group discussions. Individual interviews aim to increase the comfort and openness of participants in order to achieve a more comprehensive contextualising of their photographs. The individual interviews also allowed for a more individualised approach in order to recognise the specific communication needs of each participant. Secondly, for both the photo-taking and the individual interview, prompts were simplified and more open ended than in many photovoice projects. This decision aimed to maintain the interest of the research participants as well as produce data that were participant-driven rather than structured by the researchers (Ha & Whittaker, 2016). The teens were given full choice over when they would take pictures and when they wanted to be interviewed. By allowing the participants to choose their times for data collection, they were given some control over the research process, which is a critical component of participatory research (Bergold & Thomas, 2012). Additionally, participants could select which photographs and how many they wanted to discuss.

Summer Camp Setting

This research project was conducted over the summer 2018 at a sleepaway summer camp in Ontario, Canada, which serves children aged 6-17 years old with complex neurobiological disorders. The population of campers who attend Camp Neuro is diverse. Youth have severe and complex neurobiological disorders including fetal alcohol spectrum disorder, autism spectrum disorder, oppositional defiant disorder and attention deficit (hyperactivity) disorder and represent a higher-needs population than those at similar recreational programs. The camp relies heavily on fundraising, donors, and grants in order to provide respite for individuals regardless of their financial situation. Camp Neuro states that one of their priorities is to function as respite for the caregiver and their family and that respite is not truly restful if it causes financial stress. As a result of these institutional policies, the participants at Camp Neuro represent a diverse group of adolescents with respect to ethnicity, religious affiliation, socio-economic status, and gender identity all with high-needs and complex neurobiological disorders. Campers attend Camp Neuro for two weeks and the camp runs four sessions over the course of the summer, two for male campers and two for female.

Camp Neuro focuses on providing services to those who have not or would not be successful or even eligible for other recreational programs. The policies and staff training ensure that Camp Neuro can accommodate campers with antisocial behaviours and related challenges that would typically disqualify them from recreational opportunities. Many of their campers have either been prohibited from attending other programs or were sent home due to challenging behaviours such as aggression. Camp Neuro is one of a handful of specialised summer camps in Ontario that does not expel a camper for externalized aggression. Once a camper has been

approved for Camp Neuro, they are invited back each subsequent year until they age out at 17 years old. Thus, many of the teens in this study have attended the camp for several years.

The teen program at Camp Neuro is a separate program for campers aged 14-17. It allows campers more independence and focuses on life skills such as job preparedness. Unlike the camper program where a counsellor is with a camper at all times, teens are supported based on their needs. While many do require 1:1 support, others complete jobs or activities independently with a counsellor only checking in a few times over the hour. Each evening the teens select their schedule for the following day from a list of optional activities. Teens must complete one hour of fitness and one hour of maintenance each day, and then are allowed to fill the remaining time with whatever activities they choose. Examples of activities may include helping out with the younger cabins, spending time working on their resume, or signing out a computer to work on obtaining their boating license. The teen program also runs "Teen Talks" over the two-week session, covering topics such as healthy relationships and learning to manage your finances. The teens in the teen program are paid for their work at camp and are given their paycheque on the last day of camp.

Recruitment

Participants were recruited using an opportunistic sampling strategy (Jupp, 2006). To be eligible to participate, campers needed to be between the ages of 14 and 17 and be attending Camp Neuro during summer 2018. Additionally, participants were required to have a parent-reported neurobiological disorder. Since campers are required to have an established neurobiological disorder in order to be admitted to Camp Neuro, their enrollment at camp was sufficient support to meet this inclusion criteria. The target participants for this research were minors with neurobiological disorders, so caregivers were first contacted for consent. Caregivers were provided with an information letter and invited to ask any questions they had about the research. Once parental consent was received, the researcher talked with the camper, introduced them to the research and invited them to be involved. Both caregiver consent and participant assent were necessary for participation. Approval for this research was granted by the Laurentian University Research Ethics Board.

Data collection

Data collection occurred over two phases. Phase 1 involved having participants take pictures of what camp means to them, and during the subsequent phase 2, participants discussed their photographs during individual interviews. Participation in phase 2 was optional, provided to each participant by asking during the assent process if they would like to take pictures and talk about them, or if they preferred only to take photos. Twenty-three adolescents at Camp Neuro took photographs of what camp means to them, as per phase one, and 13 were subsequently interviewed as part of phase two.

Eligible teens with caregiver consent were introduced to the research project within the first three days of camp. If they expressed interest in taking photos, they were provided with a

digital camera to take their pictures at a time of their choosing throughout the first week. Teens at Camp Neuro select their schedule for the next day each evening, which provides them with flexibility of when to take their photographs and how much time they would like to spend taking photos. Before going to take their photos, adolescents were given the prompt "What does summer camp mean to you?" and provided with a printed copy of the guidelines for ethical photo-taking. Most significantly, participants were asked not to include anyone's face in their photographs.

If the participant had expressed interest in participating in phase 2 of the research study, they were then asked to schedule an individual interview in the same way they had previously scheduled time for taking photographs. Once again, they were free to choose the day, time and location of their interview. At the interview, participants were asked open-ended questions beginning with an invitation to tell the interviewer about their photos. Follow-up prompts included "why did you take this photo?", "how do you feel about this photo?", and "would you have taken different photographs when you were younger at camp?" and were used at the interviewer's discretion based on the comfort and openness of the participants. Interviews ranged in length from 4.36 minutes to 63.57 minutes. At the end of each interview, the participant was invited to select a pseudonym. The interviews were audio recorded and transcribed for data analysis.

Twenty-three teens took photographs at Camp Neuro, and 13 were then interviewed about their photos. Demographic data were also collected using the consent forms from the participants' caregivers (Table 2). The consent form asked parents/guardians for their camper's diagnoses, gender identity, and date of birth for age calculation. Of the 23 participants in phase 2, four identified as female and 19 identified as male. The ratio of male to female participants

underrepresents the proportion of female campers at Camp Neuro, which is about 3:2 males to females.

Pseudonym (as chosen by the participant)	Gender	Diagnoses	Number of photos
Purple	F	Anxiety	5
Craig	M	FASD, ADHD	14
Dumbledore	M	ADHD, Depression	4
John Casey	M	ADHD	18
Niminodin	M	FASD, ADHD	109
Pokémon	M	ADHD, Developmental delay	5
Cream	F	ASD	13
Toppy	F	ASD	20
Dragon	M	ASD	36
Kim	M	ASD	27
Lionel	M	ASD	11
Nick	M	ASD, ADD, Tourette's Syndrome	32
The Counsellor	M	ASD, ADHD	25

Table 2: Demographics of Interviewed Participants.

Note. FASD- fetal alcohol spectrum disorder, AD(H)D- attention deficit (hyperactivity) disorder, ASD- autism spectrum disorder.

Data analysis

The qualitative data generated by this photovoice study included the visual data of the photographs taken by participants as well as the individual interview recordings and transcripts. The researcher made use of Braun and Clarke's (2006) approach to inductive analysis to analyse the 13 transcripts. In addition to analysis of the interviews, photographs were analysed using content analysis as outlined by Ha & Whittaker (2016). To support data analysis the photographs and interview transcripts were uploaded to NVIVO®, a qualitative data management software.

Data analysis began with the familiarization of all data including the interview recordings, the verbatim transcriptions, and the photographs. The transcripts were then coded semantically, focusing on what the participants said. Coding was done inductively, which

allowed for a participant-driven analysis. Following interview coding, the entire set of photographs was analysed using a photo content analysis protocol outlined by Ha and Whittaker (2016). The 23 participants took a total of 809 photographs, ranging from four to 113 with an average of 35 (Table 2). Photographs were coded according to two pre-determined factors: focus and location, as per Ha and Whittaker (Bock et al., 2011; Ha & Whittaker, 2016). While some form of thematic analysis is common across photovoice projects, photo content analysis is not. This step of data analysis was included because of the limited verbal communication skills of the participant population. Photovoice was chosen in part to make this research project accessible to participants with diverse communication skills and so to rely solely on verbal interviews would be contrary to the inclusive aim of the research. The codes from both the interviews and the photographs were used in conjunction in the development of themes (Ha & Whittaker, 2016). The two sets of data provided a tool for data triangulation, thereby promoting the trustworthiness of the results of the study and enhancing the overall rigour of the research (Creswell, 2007; Denzin & Lincoln, 2005).

Results: "I know how to do this" (Nick)

Through data analysis, learning at summer camp was identified as meaningful to the participants and was divided into three key themes and subthemes; *I Can Do It (I Can Make Friends), Personal Growth* and *Life Lessons (Be Yourself, What is Inside Counts,* and *Direction not Perfection).* These themes explore the value of summer camp to the participants themselves, beyond its role as respite for their caregivers. The more abstract nature of these themes and sub-themes required the youth to contextualise their photos, and therefore the findings only portray the thoughts and experiences of youth that participated in the interviews.

I Can Do It

Summer camp provides an ideal environment for learning and mastering a variety of new skills. Physical, cognitive, and social skill development are not only valuable outcomes but also meaningful to teens with neurobiological disorders themselves. Five participants talked about their accomplishments at Camp Neuro and the new skills they had learned. In their interviews, they discussed the pride and satisfaction they felt when they completed a goal. Craig and Niminodin talked about their accomplishments as they related to activities; passing the kayak test to be able to kayak solo, overcoming a fear of heights, and learning to filter water on camping trips.

Kim, on the other hand, talked about Camp Neuro itself as an accomplishment. Teens at Camp Neuro have the opportunity to work on job skills during their time at camp. They are paid for contributing to the camp community through things such as maintenance jobs, helping with the younger cabins, and setting the tables for meals. Kim struggled with homesickness during his

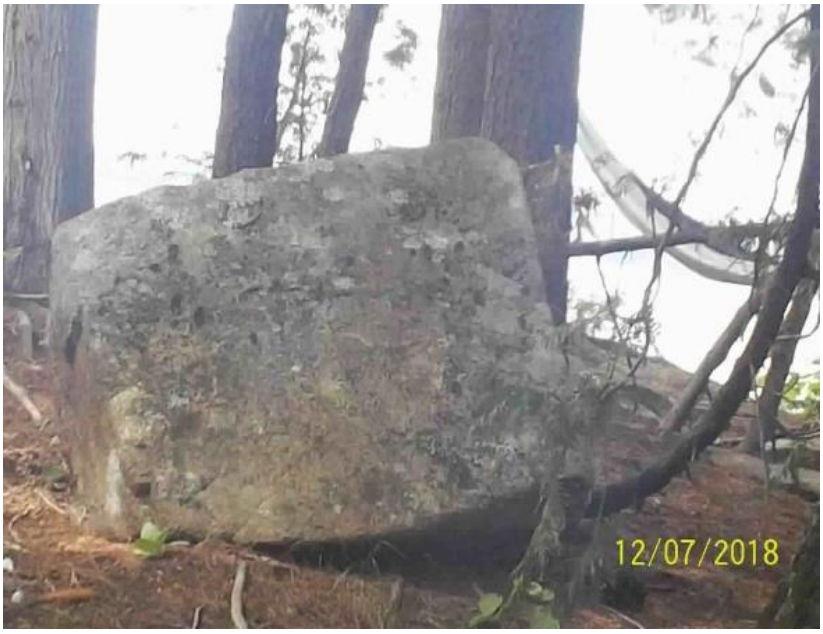

Figure 8. Kim's photograph of a rock.

camp session, something he discussed throughout his interview. He said: “This rock (Figure 8) is supposed to represent how hard like getting to work here is. I mean like, it's going to be satisfying in the end when I eventually complete Camp Neuro but like, this session, but like it's hard work.” He went on to say, “you kind of do feel satisfied in the end. I'm pretty sure like even though this, the last couple days have been hard for me and it's probably going to get harder later in the session, I think I'll be, I think I'm gonna be satisfied by the end”.

In addition to the feeling of accomplishment, two participants talked about the opportunities that summer camp provided them to show off their skills. Dragon and Craig discussed their pride in showcasing their abilities for staff and other campers. Dragon said that having the piano in the dining hall at camp has allowed him to “demonstrate [his] intellectual skill in piano performance and the practical playing of the piano”.

I Can Make Friends

In addition to personal accomplishments, participants also talked about social skill building and social accomplishments. Nine participants talked about their friends at camp and four talked specifically about learning social skills and viewing making social connections as an accomplishment. Cream talked about finding making friends challenging because of her autism spectrum disorder. She went on to say that at camp, in a cabin with four other girls, she feels less alone and recognises that she “is actually socializing with people”. Niminodin and Purple also talked about developing social skills at Camp Neuro. For younger campers, one hour of their day is dedicated to learning social skills. Activities include board games to learn how to take turns, follow rules, and lose graciously, and organised team sports to practice playing fairly and as part of a team. In this way, social conventions that may come naturally to other children are taught as skills. Niminodin said that through summer camp, he developed skills for making and keeping

friends, and learned to be a more patient person. Purple similarly said that at summer camp she learned “friendship building activities” that helped her to make meaningful connections with her peers (Figure 9).

Figure 9. Purple's photograph of one of her peers.

Personal Growth

Five participants talked specifically about their personal growth at Camp Neuro. They all discussed the role of Camp Neuro in helping them mature. Niminodin, who was graduating from camp at the end of his session and had been attending since the age of seven, reflected on his time in the campers’ lodge, which is the building where the youngest campers sleep (Figure 10). He described the lodge as a place where “the campers experience maturity and the values and responsibilities and priorities. It's a good place to build campers”.

Figure 10: Niminodin's photograph of the younger campers' lodge (edited to protect the identity of Camp Neuro).

Craig also talked about growing and learning to be a good person while at Camp Neuro. Craig is diagnosed with FASD and ADHD and he credits cadets and summer camp in shaping his personal growth. In his interview, he discussed his behavioural challenges as a younger kid describing himself as “annoying”. He said: “I was always misbehaving and that like I was always getting into trouble. Over the years, I have definitely straightened up my act and Camp Neuro has definitely helped me with that”.

Life Lessons

At the end of many of the interviews, the interviewer asked the participant to sum up the meaning of Camp Neuro from their perspective. It was in response to this question that many participants talked about some of the profound and wide-reaching lessons that they had learned at Camp Neuro. The following are three important lessons from the perspective of the participants; *Be Yourself, What is Inside Counts*, and *Direction, Not Perfection*.

Be Yourself

Five participants talked about the broad life lesson of being yourself. Toppy said that Camp Neuro really gave her the support and confidence to be herself. Similarly, Purple summed up Camp Neuro as her "safe place" and space where she can be who she is. Along the same vein, Nick and Lionel talked more broadly about the idea of fitting in. Nick said that at summer camp, campers do not need to worry about "judgement and stuff". Lionel echoed this sentiment, explaining that for him, Camp Neuro represents a place where "people can fit in and enjoy themselves".

By far, it was Craig who talked the most about the idea of being yourself. The concept appeared to be incredibly important to him. He discussed the value of space to be yourself specifically for young people with disabilities: "If it wasn't for [the directors], I wouldn't be [at Camp Neuro]. They made it possible for people like me, people with disabilities, for them to be themselves. They don't have to pretend anymore. People don't realise what kids with disabilities go through every single day".

What is Inside Counts

Two participants talked about learning about their intrinsic value at Camp Neuro. Intrinsic value is a personal measure of worth that may help to build self-esteem (Pekrun, 2014).

Purple said that “camp taught me that… even if it’s flawed, it’s still beautiful. And before camp, I had trouble realizing that but at camp it kinda opened me up to new possibilities” (Figure 11).

Figure 11. Purple's photo: "even if it's flawed, it's still beautiful"

Craig also discussed the importance of inner beauty in connection to being yourself. He talked about the reality that many kids are bullied for their disabilities, their appearances, and for being different. He went on to say that he sees many of his peers on Facebook talk about feeling ugly or stupid. He credits summer camp with his understanding that everyone is unique:

> So many people have said that they’re stupid, they’re ugly. But some people haven’t realised, no matter, it doesn’t matter what you look on the outside, what matters is what you look like on the inside. It matters about your personality. It doesn’t matter if you’re, if you look different. People don’t realise that you’re special. You are unique.

There is no way to change it, even with surgery. You'll always be special. In your own way.

Direction, Not Perfection

Lionel was the only participant who talked about "direction, not perfection", but it is an important result to discuss. The phrase "direction, not perfection" is a motto at Camp Neuro used by both campers and staff. It reinforces the idea that each camper and child is unique, and the goal is to move forward with improvements, but perfection is not always attainable or necessary. To Lionel, that phrase gives him "words to live by. Kind of like camp is a place to get you on the right path" (Figure 12).

Figure 12. Lionel's picture of his t-shirt (edited to protect the identity of Camp Neuro).

The participants discussed learning a wide variety of physical, cognitive, and social skills at Camp Neuro, as well as broad life lessons. The outcomes that participants identified as having learned at summer camp have impacted their lives and influenced their personal growth from childhood into adolescence.

Discussion

Photovoice provided teens at Camp Neuro an opportunity to share their experiences at summer camp. The combination of photographs and individual interviews resulted in rich descriptions from the participants' points of view. The results support the concept that recreational summer camps for youth with neurobiological disorders have meaning beyond their role as a respite service for caregivers by exploring what meaning the campers themselves ascribe to attending Camp Neuro.

Current research into respite services for caregivers with an adolescent with a neurobiological disorder has almost exclusively focused on the experiences of the caregiver (Pollock et al., 2001; Whitmore, 2016). Particularly with recreational programs that double as respite services, youth with neurobiological disorders are not passive recipients but rather are active participants. What this means is that while the program may benefit caregivers, it is the youth who are engaged and participating in the actual program and who ultimately should have their voices heard and their needs addressed. At Camp Neuro, the camper-centered focus is particularly true due to flexibility for the teens to choose what they want to do with their time at camp within the parameters of their program. The participants have clearly outlined a collection of meaningful learning experiences that are the result of their engagement in summer camp. Positive learning outcomes are common for youth at summer camp programs in general. Children and teens at summer camp learn social skills for positive interactions, cognitive skill

building such as problem-solving skills, and physical skill building with exposure to new activities (Pharr, 2018; Philliber Research Associates & American Camp Association, 2005). For youth with neurobiological disorders at specialised summer programs such as Camp Neuro, the potential for learning outcomes persists. The results from the participants at Camp Neuro provide support for the idea that with support to meet each campers' needs, positive learning outcomes are just as possible.

The narratives from the Camp Neuro participants are quite different compared to those from photovoice projects with similar participants. In a study by Cheak-Zamora, Teti, and Maurer-Batjer (2018) concerning youth with autism spectrum disorders in Missouri, photovoice was used to explore their feelings about the transition from adolescence to adulthood. The teens in this study expressed feelings of jealousy towards peers and not feeling as good as others (Cheak-Zamora et al., 2018). Alternatively, in the context of Camp Neuro, participants in this study discussed feelings of pride and accomplishment. It is possible that the more level playing field created by being surrounded by peers with similar disorders provided the teens with increased confidence to explore and showcase new skills. Participants in the Cheak-Zamora et al. study (2018) also discussed social isolation and a lack of quality friendships. Additional studies have suggested that youth with autism spectrum disorder have small social circles and are less likely to have reciprocal friendships compared to typically developing peers (Mazurek, 2014; Petrina, Carter, Stephenson, & Sweller, 2016). Again, social outcomes in this study were very different. The teens at Camp Neuro discussed the positive effect of learning social skills and the friendship potential that summer camp provides. While four teens did share negative feelings during their interviews, they were infrequent and inconsistent. For example, Dragon expressed

frustrations with some of the staff when they restrict his activities, while Craig expressed feeling sad that one staff had not returned to work at Camp Neuro that summer.

In the current study, participants were not directly asked about the links between what they have learned at camp and other aspects of their lives. That being said, Craig did speak unprompted about how personal life and camp experiences have interacted to contribute to his learning. Craig was the participant who discussed learning that it is what is inside that counts. In his interview, he talked about seeing his peers on Facebook saying, "that they're ugly or they're stupid". He went on to say that camp is where he learned that everyone is special and the value of accepting people as they are. This lesson, he said, has prompted him to respond to his peers with compassion, saying; "no you are not stupid, no you are not ugly. You are beautiful and intelligent in your own special way". From Craig's discussion, it can be suggested that summer camp is more than just the two weeks that the participants spend at Camp Neuro, and the lessons that they learn extend beyond the boundaries of camp. Instead, the things that the participants have learned at camp may be substantial in influencing their personal lives as well.

While it is unrealistic to definitively ascribe universal characteristics to all individuals with neurobiological disorders, many do have difficulty with abstract thinking (American Psychiatric Association, 2013). In particular, youth with autism spectrum disorder and intellectual disabilities often think in very concrete terms and are more comfortable discussing the present than recalling the past or imagining the future (Bowler et al., 2007; Crane & Goddard, 2008; Terrett et al., 2013). The results of this study are insightful and the discussions that the participants engaged in showed a deep understanding of their experiences at summer camp. Not only did they discuss their history at Camp Neuro, they astutely explored the future impact of what they learned at camp. The use of photographs as a tool for communication was

likely vital to the participants' discussions as they moved from concrete photographs to abstract thoughts. The richness of the results also provides support for continued exploration into methods for engaging individuals with neurobiological disorders and intellectual disabilities in research. Making research more accessible to these populations allows them to communicate their perspectives and influence decisions on the things that affect their day-to-day lives such as respite services and recreational activities.

While social action is an important part of photovoice research, it was not the primary goal of this project. First and foremost, this project intended to amplify the voices of youth with neurobiological disorders and provide a platform for their expression. As a result, the focus was to encourage engagement in research and creative expression, not social action, a goal that is reflected in projects with similar populations (Teti et al., 2016). The researcher's engagement with Camp Neuro will continue, however, and in partnership with the research participants, an exhibit of the photographs and key quotations will be produced. The exhibit will showcase photographs and quotations from the participants to caregivers, decision-makers and funders within Camp Neuro and related camp programs in an effort to influence programming to the benefit of the participants and the next generation of campers.

There were limitations to this study. The results come from a specific population of youth with neurobiological disorders at a single recreational program in Ontario. The results are therefore not generalizable to all youth with neurobiological disorders or all disability-specific recreational programs because of the unique population of campers and the distinct staff support and programming offered by Camp Neuro. Rather, they provide insight into a limited population's perspectives who are often excluded in research. Additionally, the researcher was not involved in the photo-taking phase of the study in an effort to limit influence on the

photographs that the participants took and ensure participant-driven data. While all of the direct support staff did receive training at the start of the summer on the appropriate ways in which to support campers taking photos, there was no direct oversight from the researcher to ensure that the staff were not influencing the photographs taken.

The current study's findings were also limited by who was represented. While Camp Neuro is primarily attended by high-needs individuals with complex neurobiological disorders, there is still a spectrum to this population. Higher-needs individuals, including non-verbal participants, only took part in the photo-taking portion of the study. As a result, the contextualising of photographs was exclusively done by verbal participants many of whom are less impacted by their disorders. This trend in representation is not exclusive to Camp Neuro but rather mirrors what has occurred generally in neurobiological activism.

The community of individuals with neurobiological disorders has largely embraced the notion "nothing about us without us", however, their views on categorizing neurobiological disorders vary. In the autism community, many vocal activist members have advocated for autism spectrum disorder to be considered an identity and community as opposed to the biomedical category of disease (Bagatell, 2010). Others, however, do not dismiss the biomedical model outright in hopes of a potential cure. In particular, it tends to be higher-needs individuals who are more severely impacted by their disorder, who align themselves with the cure perspective (Bagatell, 2010). In general, high-needs individuals are less likely to have their views heard or represented by both research and activism. Future studies should address this discrepancy and ensure the availability of a variety of communication tools in order to increase the accessibility of research to a broader spectrum of people with neurobiological disorders.

Similarly, while Camp Neuro has approximately 40% female campers, this study only had four participants out of 23, which is less than 20%. It is unclear why there was such low interest in participating from female campers. Females with neurobiological disorders are frequently underrepresented in research (Cheak-Zamora et al., 2018; Ha & Whittaker, 2016), possibly due to differences in presentation of disorders between males and females, which can influence the identification and diagnosis of neurobiological disorders in females (Loomes, Hull, & Mandy, 2017). The perspectives of females with neurobiological disorders is lacking in research studies and efforts should be made to increase their engagement in order to shape programming that suits their needs and wants.

The results of this study support summer camp experiences as valuable to youth with neurobiological disorders. The participants spoke passionately about what they had learned and described how summer camp had shaped their development and their lives. Camp Neuro also gave the teens an opportunity to connect socially with their peers and develop strong relationships. Recreational programs must consider what their participants need or want to learn in order to ensure that they are not only providing caregivers with much needed respite but also important skills and outcomes to the youth that they serve. It is clear from the results at Camp Neuro that summer camp programs have tremendous potential to provide youth with neurobiological disorders support in their cognitive, social, and emotional development in a way that is meaningful to them.

Conclusion

Adolescents with neurobiological disorders are a unique complex group that has historically been excluded from research. This study supported youth to discuss their perspectives about their experiences at Camp Neuro, a specialised sleepaway summer camp. The

results from this research support summer camp as a valuable experience for the participants themselves, beyond simply providing respite for their caregivers. The adolescents at Camp Neuro discussed valuable life lessons and the ways in which the supportive camp environment assisted their personal growth. By demonstrating the capacity of youth with neurobiological disorders to participate meaningfully in arts-based research, this photovoice project demonstrates the importance of including youth with neurobiological disorders in academic research.

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Chapter 4: Discussion

4.1 Summary of Results

Recreational opportunities can be a valuable contributor to a child's development and can result in positive physical, social, cognitive and emotional outcomes (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012; King et al., 2003). For youth with neurobiological disorders, physical, social and institutional barriers often prohibit their participation in integrated, or even some disability-specific, recreational programs (Anaby et al., 2013; Dahan-Oliel et al., 2012; Heah, Case, McGuire, & Law, 2007; Mulligan et al., 2012). As a result, programs such as Camp Neuro provide recreational programming to a high-needs population of youth with neurobiological disorders who are often otherwise excluded from mainstream opportunities. Most of what is known about youth with high needs in sleepaway or respite programs is caregiver or staff reported. The perspectives of the youth themselves is needed to inform recreational programming and ensure that the services available to children and teens with neurobiological disorders are meaningful to them. The results of this thesis represent the perspectives and experiences of youth with neurobiological disorders at Camp Neuro. Analysis was conducted and guided by the research question: "How do adolescents with neurobiological disorders at a disability-specific sleepaway camp in Ontario make meaning of their summer camp experiences?".

The interviews and photographs were analysed sequentially beginning with thematic analysis of the interview transcripts (Clarke & Braun, 2014) and followed by content analysis of the photographs (Ha & Whittaker, 2016). The results were organised into two top-level themes; *The Camp Environment* (Chapter 2) and *What I Learned at Camp* (Chapter 3). Analysis of the data was done using a semantic, inductive approach. The results therefore present a descriptive

account of the participants' perspectives, largely in their own words and using their own images. Many of the codes and themes are quotations from participants in an effort to more accurately represent their experiences.

4.1.1 The Camp Environment

Physical, social and emotional aspects of the camp environment were captured in the participants' photographs and discussed throughout the interviews. All 809 photographs taken by the research participants were taken around Camp Neuro and capture the camp environment. The content analysis of the focus on the photographs divided the pictures into *animal, food, nature, object, person,* or *place.* Only 18 photographs were coded as an *unknown* focus. Many photographs were taken of typical summer camp scenes, with 166 photos of nature and 133 of places around camp such as buildings or the playground. Additionally, 52 photographs were of people, depicting the social environment of Camp Neuro. The photographs were contextualised by 13 of the participants in the individual interviews. Teens answered the question "what does camp mean to you?" with descriptions of activity areas, the outdoors, relationships with campers and staff and feeling at home at Camp Neuro that were prompted by many of the photographs they took. Both the photographs and the subsequent interviews provided insight into the participants' perspectives on the camp environment.

The existing literature that does explore special needs campers' opinions on summer camp has done little to take into account the camp environment (Clark & Nwokah, 2010). Research is often pre- or post-reported and as a result, the reported outcomes may not truly represent the summer camp experience (Clark & Nwokah, 2010). This photovoice project was fully conducted with the participants while they were at camp. Therefore, all photographs were taken at Camp Neuro, which allowed participants to discuss the present in concrete terms rather

than asking them to think of the past or imagine the future, which may be challenging for many youth with neurobiological disorders (Bowler et al., 2007; Crane & Goddard, 2008; Terrett et al., 2013). The insights into the environment highlight what is important to the participants themselves. For example, the 166 photos of nature and eight participants who talked about the value of nature in phase 2 suggest that the opportunity to spend time outside was important to many of the participants. One participant elaborated and talked about how being at summer camp is important because it brings campers together with nature.

In addition to the physical environment, participants also discussed the importance of the social and emotional environments at Camp Neuro. The opportunity to participate in social recreation is important for school aged children and adolescents, and the social environment can either facilitate or hinder the extent of that participation (World Health Organization, 2007). Participants at Camp Neuro talked about the value of having peers and staff who were supportive and welcoming. This social environment contributed to an emotional climate of comfort and happiness for most of the participants. Two participants talked about negative emotions. Kim discussed his homesickness while Dragon talked about his frustrations with younger campers and some of the staff. Both, however, went on to say that they felt that their overall experiences had been positive. It is likely that the physical and social environments at Camp Neuro contributed to the positive emotional climate that the participants described.

Many of the aspects of the camp environment that the participants discussed would be found at other traditional summer camps. For the high-needs adolescents at Camp Neuro, it is the individualised supports and accommodations that create an opportunity to be successful at summer camp. The participants talked about the fact that Camp Neuro provides them with patient and supportive staff and unique accommodations for behavioural challenges, learning

difficulties or compulsive routines. This level of support is unique and crucial to the successful participation in social recreation for youth and teens with neurobiological disorders.

4.1.2 What I Learned at Camp

The second group of themes captured the new skills the participants had learned, personal growth, and life lessons from summer camp and it quite clear that Camp Neuro is more than a place for caregiver respite. Learning was explicitly mentioned in seven of the 13 interviews, with many participants discussing a variety of different skills and lessons they had taken from their time at camp. Most frequently the discussion focused on physical skills such as kayaking, rock climbing, and wood working but others talked about learning how to make friends or becoming more aware of their own style of learning.

In his interview, Nick talked about learning to recognise plants in the garden, one of the activities offered at Camp Neuro. He said that when you know how to recognise mint by rubbing the leaf and smelling it, you know that you have mastered that skill. While Nick may not have used the term *mastered* intentionally, it is an important aspect of skill building at Camp Neuro. Mastery standards are individual, meaning that each child can be successful by achieving the goal (Pekrun, 2014). Mastery is also connected with experiencing more opportunities to display skills (Bean et al., 2016). By focusing on mastering skills, teachers and camp counsellors can strengthen youths' self-confidence and positive emotions as well as help to develop physical, cognitive, and emotion skills (Bean et al., 2016; Pekrun, 2014). While the participants talked primarily about their exposure to a variety of new skills, it is likely that the opportunity to master those skills has wider implications for their self-esteem that go beyond the act of, for example, learning to stern a canoe.

The two sets of data (the visual data in the form of photographs and the interview transcripts) provided complementary information about the participants and their experiences at camp. The content analysis of the photographs was concrete, capturing the focus and location of photos. Similarly, participants who were interviewed were largely prompted by their own photographs to discuss the camp environment. On the other hand, the second theme, *What I Learned at Camp,* encompassed abstract ideas such as emotions and ideas as opposed to physical objects captured in photographs. While the two themes may seem distinct, they were in fact deeply intertwined. This connection between physical space and social and emotional relations is well supported by health geography where it is acknowledged that these factors all represent different dimensions that influence well-being (Severson & Collins, 2018).

The photo content analysis, as outlined by Ha and Whittaker (2016), did not directly inform the *What I Learned at Camp* themes. Initially, it seemed that the deep discussions about what participants learned at Camp Neuro occurred unprompted and were simply the result of participant-driven interviews. However, by repeatedly listening to the recorded interviews and reviewing the accompanying photographs, as well as reviewing field notes made following the interview, it seemed that this was an oversimplification of what had occurred during the interviews. While the ideas and concepts captured within the *What I Learned at Camp* themes consisted of abstract ideas and were not physically represented in photographs, they were absolutely prompted by the photographs. Some connections were made seemingly in the moment in a sort of stream of consciousness. Lionel presented a photograph in his interview of himself wearing a t-shirt with the words “direction not perfection” printed on it. When asked what that phrase means to him, he said he did not know. He took a long pause before answering “words to live by, I think”. He elaborated that he felt that Camp Neuro is a “place to get you on the right

path". This was not an answer he had prepared in advance but was rather prompted by his own photograph while in the interview.

Other themes were more directly captured by representative photos. For example, Kim took a photograph of a rock that was coded in the content analysis as *rock* under focus and *cliff* under location. In the interview, however, he explained that the rock was representative of how much hard work there is to do at Camp Neuro and his difficulty with managing homesickness. Again, these were insights that were not captured by the photographs and required contextualising using insights from the participants' interviews.

4.2 Methodological Rigour and Significance

Photovoice was a beneficial method for engaging youth with neurobiological disorders and achieving rich insights into their experiences at Camp Neuro. The method is participatory in nature, which means that the focus is on conducting research with the participants in a collaborative way (Bergold & Thomas, 2012). Researchers have suggested that a participatory approach to research with youth with neurobiological disorders may result in more authentic data that are grounded in the social reality of individuals with neurobiological disorders (Jurkowski, 2008). Additionally, the participatory method provided insight into the physical, social, and emotional experiences of the participants at Camp Neuro that would typically be inaccessible to researchers because of inability of many mainstream research methods to engage this population (Jurkowski, 2008). This study also took a strengths-based approach to photovoice in lieu of the deficits model that has frequently been used when conducting research with or about individuals with neurobiological disorders (Teti et al., 2016). The research question focused on the participants' experiences at summer camp and allowed participants to guide the data collection based on what they wanted to capture as opposed to the limitations of their diagnoses. The

prompts for photo-taking and the interview also asked participants about what they would change about camp and what challenged them, as opposed to what they disliked. The use of a strengths-based approach was beneficial in identifying strengths-framed education and skills programs for youth with neurobiological disorders to work towards positive learning and development opportunities for this population (Teti et al., 2016).

Rigour in qualitative research refers to the trustworthiness of and confidence in the results of a research study (Thomas & Magilvy, 2011). As it relates specifically to participatory research and photovoice, rigour is incorporated into every stage of research (Lennie, 2005). Rigorous photovoice research requires the researcher to continuously question their assumptions as well as to reflect on how the wisdom and expertise of a given community is being both honoured and represented (Lennie, 2005; Liebenberg, 2018). This thesis was framed by critical disability theory, which asserts that disability is experienced due to the interaction between individual impairments and the barriers linked to an ablest society (Gabel & Peters, 2010; Schalock, 2004). The theoretical underpinnings assume that reality is created by individuals, which challenges the standard of reaching a universal truth in quantitative research (Thomas & Magilvy, 2011). As such, rigour must be critically considered in order to increase the likelihood that the results of the current study will be seen as credible and used to inform relevant programs and policies (Lennie, 2005; Thomas & Magilvy, 2011).

There are a number of ways to demonstrate rigour in qualitative participatory research and photovoice studies including prolonged engagement and triangulation (Lennie, 2005; Lincoln & Guba, 1985; Morse, 2015). The use of participatory methods such as photovoice has been suggested to improve the validity the research because it allows for a more accurate representation of the participants' beliefs and knowledge as they relate to the research question

(Jurkowski, 2008). While my engagement with Camp Neuro and the participants was not exclusively within the confines of this research project, my prior experiences and visibility around the camp likely contributed to increased trust between my participants and me, and may have increased the depth of the descriptions during the interview portion of data collection. A critical analysis of the strategies for achieving rigor in qualitative research by Morse (2015) suggests that prolonged engagement is not necessary in interview research. However, because of the complex needs of the participants in this research, I believe that prolonged engagement was beneficial in increasing their openness during the interviews. Additionally, in a similar way that prolonged engagement may reduce observer effects in ethnographic research, it may also result in more honest interviews than would have otherwise been achieved (Garton & Copland, 2010). Data triangulation was also used in the current study. Because both the interview and photograph data were coded and included as equally valuable sources of information, the development of themes was reliant on two sets of data (Lincoln & Guba, 1985). Additionally, the use of two forms of data collection allowed for the inclusion of a diversity of participants compared to if it was required that every participant partake in an interview in order to be included (Lennie, 2005). The results of this study were further verified by triangulation with related literature including quantitative research on the topic on summer camp for youth with neurobiological disorders (Clark & Nwokah, 2010; Dahan-Oliel et al., 2012; Ha & Whittaker, 2016).

Both positionality and reflexivity were important aspects of this research project and were essential to enhance the rigour of the study. Data collection was driven by the participants by having an open-ended prompt to both the photo-taking and the interviews, by allowing participants to select which and how many photographs to discuss, and by allowing participants to guide the conversational interviews. The data, however, are a product of the interaction

between the researcher and the participant. The initial positioning and reflexive work that I did at the start of this thesis can be used to emphasise the unique relationship between participant and research that is at play in this project. I had three years of previous experience with Camp Neuro. Not only did this contribute to my relationships with the participants, it also affected who I was as a researcher. My previous training and experience potentially made me more open to including individuals with neurobiological disorders in research and listening to their experiences. Additionally, the exposure I had received in years of involvement likely eroded many of the stereotypes that typically developing people have about the abilities of individuals with neurobiological disorders. As a result, my interaction with the participants of this study was unique and contributed to the depth of the results.

Methods for ongoing critical reflection built upon the initial reflexive practice and were important for enhancing the overall rigour of the project (Lennie, 2005). The reflexive practice was used to identify the lens through which this research was conducted. Over the course of the research process, I engaged in frequent memoing. I recorded my thoughts, impressions and decisions through the development of the project, data collection and analysis, and continued through the writing process. Fieldnotes that were recorded during the individual interviews were entered alongside the photographs and interview data in the QSR NVIVO® software as important sources of contextualising information. For example, Kim was particularly emotional during his interview and talked frequently about his homesickness. It was noted that Kim chose to be interviewed immediately following a group discussion with all of the teens at Camp Neuro to inform them that one of their cabin mates had gone home due to the death of his mother. While this insight does not necessarily change the data, it does provide greater context for Kim and the topics that he chose to discuss. Finally, member checking will be used to ask participants

to also take part in reviewing the results of the project and to check the researcher's interpretations (Lennie, 2005), though this has not been completed to date. The member checking will be combined with the social action component of the photovoice project in an effort to reduce the time burden demanded of participants. This component will be discussed later in the chapter.

The use of qualitative, arts-based research methods with populations with limited verbal communication skills or cognitive deficits is limited but increasing. Adolescents with neurobiological disorders have frequently been assumed to have limited knowledge regarding their own lives and control is typically given to caregivers, health professionals, or researchers (Jurkowski, 2008). Many recent studies have largely explored the overall idea of using photovoice to engage youth with a range of neurobiological disorders and have discussed the benefits and challenges of the methodology (Ha & Whittaker, 2016; Jurkowski, 2008; Teti et al., 2016). The results of these studies were helpful in designing the methodology of the current study and their results were further supported by the current research. Photovoice is described as a flexible methodology that can accommodate the communication and motor skills needs of a population with neurobiological disorders. For example, depending on the fine motor skills of a participant, a digital camera, cellphone, or tablet were all able to be used to capture their photographs. Beyond research that discusses the benefits and challenges of photovoice with populations with neurobiological disorders, some research has begun to employ photovoice to explore specific research questions. A study by Cheak-Zamora, Teti, and Maurer-Batjer (2018) used photovoice in a more focused way to explore the transition to adulthood with youth with autism spectrum disorder. The current thesis used the broader exploratory literature to effectively employ photovoice with teens with neurobiological disorders while also building upon the

previous studies in the field to use photovoice to specifically ask teens with neurobiological disorders about their experiences at summer camp.

The current study relied on both photographs and interviews as important forms of data due to the potential communication limitations of the participants. The incorporation of content analysis of the photographs was valuable to complement the conversational interviews and increase the accessibility of the research project (Ha & Whittaker, 2016). Notably, people were the focus of 52 photographs. Twelve of the 13 interviewed participants talked about the people at camp during their interviews for a total of 79 coded references to friends, campers, and staff. The combination of both the photographs and the interviews underscores the importance of people to the research participants. The number of photographs of people is particularly surprising due to one of the ethical stipulations that prevented participants from taking photos of people in which they could be recognised. As a result, if participants wanted to include themselves or others in their photographs, they were required to be creative with their framing, such as taking the photograph from the neck down, or in positioning their subjects, such an having them face away from the camera. It is often assumed that because individuals with neurobiological disorders may experience social deficits, such as challenges with verbal and non-verbal communication, they are not interested in socialising (American Psychiatric Association, 2013; Ha & Whittaker, 2016). A photovoice project by Ha and Whittaker (2016) with seven children with autism spectrum disorder similarly reported a high number of photos related to social connection, with a total of 30% of photos taken including either people or group activities such as birthday parties. These high numbers of photos representing social relationships challenge the stereotype that individuals with neurobiological disorders, autism spectrum disorder in particular, are not interested in people. Ultimately, in the current study, it was the combination of the photographs

and the contextualising interviews that provided richer insights into the perspectives of the participants.

The use of photovoice is being used in increasingly specific research and leading to meaningful and impactful results. The insights gleaned by photovoice suggest that the methodology can and should be used to explore more areas of the lives of individuals with neurobiological disorders. This study provides support for the use of the photovoice methodology to explore research questions with youth with neurobiological disorders that previously would likely have been directed towards caregivers and staff. The flexibility of the methodology not only applies to health and wellbeing research, but also beyond, to promote the use of photovoice to explore the experiences of youth with neurobiological disorders in educational settings, social and romantic relationships, and beyond (Jurkowski, 2008).

Additionally, photovoice has significant implications for the growing neurodiversity movement and activism in neurobiological communities (Bagatell, 2010; Kapp et al., 2013). Photovoice increases the accessibility of research by removing the qualifications that demand research participants have the ability to read, write, or communicate verbally. It also gave participants a method of communication more suitable for abstract thoughts and ideas that can be difficult to put into words. It was really through the photographs as a conduit that many of the participants were able to communicate more complex feelings. Additionally, it emphasises the importance of lived experience and recognises the knowledge that community members have. It is these tenants that uphold the idea of "nothing about us without us" (Bagatell, 2010) by acknowledging the right for individuals with neurobiological disorders to represent their own perspectives and speak to the policies and programs that influence their lives.

4.3 Limitations

While there was demonstrated rigour to this research study, there were also limitations. The study was conducted at a single sleepaway camp for youth with neurobiological disorders. While many of the results are valuable and may be useful for program development with other summer camps and organizations that offer similar recreational programs, they are not inherently transferable. However, efforts have been made to provide a full contextual description of the participants, Camp Neuro, and the research in order to allow readers to determine what about the results resonate when considering different settings or populations (Connelly, 2016).

A potential limitation also lies in the degree of contextualization that occurred in phase two of data collection. Traditionally in photovoice research, there is a more significant emphasis on contextualizing the photographs and typically photographs that were not discussed are not included (Wang & Burris, 1997). In most photovoice projects, researchers do not specify the handling of visual data or the details of their analysis of the photographs are unclear (Ha & Whittaker, 2016). While the current study was inspired and guided by the work of Ha and Whittaker (2016) as rationale for inclusion of both visual and textual forms of data, it is possible that the relatively low percentage of photographs that were directly discussed in interviews may have limited the insight into the meaning behind many of the photographs. All of the photographs that were submitted to the researcher were treated as equally and assumed to have been taken intentionally in order to avoid assumptions about which photographs were meaningful. However, it is likely that in the more than 800 photographs, some were accidental. As a result, there was likely some error in the content analysis of the photographs, which represents a limitation to handling visual data without clear contextualisation from the photographer.

There were also limitations related to the participants in terms of representativeness. Higher-needs campers only participated in phase one of the research project. No non-verbal campers were represented in phase two, the interview portion of the study. As a result, their perspectives and experiences are not represented as in-depth in the results. High-needs individuals with neurobiological disorders often rely heavily on routine. Disruption to their daily schedule may result in increased anxiety or other negative emotions and these may be externally expressed in increased challenging behaviours. While photo-taking was more easily included in the daily schedule by replacing another activity, an individual interview was a greater disruption. Interviews are not at all similar to any of the activities at Camp Neuro. Additionally, they are more emotionally involved and rely heavily on verbal communication, a skill that may be difficult or impossible for higher-needs campers. Overall, while the photo-taking was accessible to all potential participants, the interview portion of the research project was not and resulted in an underrepresentation of the perspectives of higher-needs individuals in the contextualisation of photographs.

Females were also underrepresented in this study. Historically, the proportion of males and females with autism spectrum disorder was estimated to be four to one, as stated in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorder* (2013). This statistic has been challenged frequently and critiqued due to differences in how neurobiological disorders often present in young girls and boys. These differences may reduce the likelihood of young girls being diagnosed. Researchers in the United Kingdom systematically calculated an estimate using a meta-analysis (Loomes et al., 2017). They suggest that the male to female ratio is more likely approximately three to one for autism spectrum disorder diagnoses. At Camp Neuro, female campers are approximately two thirds of the summer population. However, in this study, only

three of the 13 interviewed participants identified as female. The opportunity for gender comparison in the data analysis was informative but requires caveats due to the small sample size of female campers. Not only are females often overlooked medically with regards to diagnoses, they are also frequently underrepresented in research (Loomes et al., 2017). While the participation from female campers with neurobiological disorders is unique and valuable, females were still underrepresented when considering the proportion of females in the camp and general population and is a limitation to this study.

4.4 Implications and Future Directions

The unique perspectives provided by the youth with neurobiological disorders led to results that have implications for both programming and research. At the programming level, the results from the teens suggest that the opportunity to connect socially with others with similar lived experiences is meaningful to them. Social connection outcomes support the continued availability and value of both integrated and disability-specific recreational programs. With regards to research, this study shows the benefits of engaging youth with neurobiological disorders in arts-based studies. By engaging youth with neurobiological disorders in research, their perspectives will be explored and represented and can be used to inform decisions that affect their lives.

4.4.1 Implications for Practice: Recreational Programming

Recreational programs should reconsider the current model of inclusive recreation, specifically the level of accommodation and support needed to truly include those with neurobiological disorders alongside typically developing peers in mainstream programming. While integrated programs are the most common option for youth with a disability or disorder, this study suggests that there are benefits to a disability-specific model of recreation particularly

in the current social climate. With adequate support and accommodation to meet their needs, youth with neurobiological disorders may be successful participants in inclusive recreational programming. However, currently, many are disqualified as programs are unable or unwilling to provide support to higher-needs individuals and those with aggressive or antisocial behaviours (Easter Seals, n.d.; Jones, 2003; Schleien et al., 2014; Shields & Synnot, 2016).

Significantly, the majority of the answers to the question "What does summer camp mean to you?" were not disability-specific. Only six of the 13 interviewed participants made any mention of their disorders or the fact that Camp Neuro was a specialised program. Even those six only spoke briefly about accommodations or challenges associated with their disorders. The rest of the interviews were spent discussing things like activities they like to do or staff with whom they have meaningful relationships. These are aspects of summer camp that are common to many different types of programs, not just specialised, disorder-specific programs. The result of the interviews with participants at Camp Neuro supports a model of camp that simply lets kids be kids, with adequate support and accommodation for their neurobiological disorders.

While typical recreational programs often have a multitude of desired or intended outcomes, the primary goal is usually to provide youth with fun recreational experiences among peers. At Camp Neuro, Purple talked about her meaningful relationships with other teens at camp. Toppy described how much fun she has on the high ropes course and Nick explained that summer camp gives him an opportunity to have fun outside. Every single one of the 13 interviewed participants had something positive to say about their time at summer camp with many discussing similar experiences with friends, staff and activities while at Camp Neuro. Recreational programs should strive to provide adequate supports and accommodations for all

program participants in order to increase the accessibility of their programs and allow all children to have fun at summer camp.

Both inclusive and disability-specific recreational programs must also integrate social opportunities for youth with neurobiological disorders. Many interviewed participants discussed the social relationships they had formed at Camp Neuro and the social skills they had learned. Youth with neurodevelopmental disorders, particularly those with behavioural challenges, are often excluded from social spaces and may face social isolation. A thematic analysis of the literature exploring recreational participation in children with neurodevelopmental disabilities by Dahan-Oleil and colleagues (2012) suggests that opportunities to participate in social programming is associated with fewer depressive symptoms and subsequently great quality of life. Their thematic analysis also suggested that recreational and leisure programs provide youth with an opportunity to practice social skills and develop friendships. Nine participants at Camp Neuro discussed experiencing positive social outcomes as a result of their time at camp. Some spoke directly about the process of learning to make friends such as Purple, who explained that camp taught her "new friendship building activities" and went on to describe her close relationships with the people she calls her best friends from camp. Others told stories about their friends at camp, such as Pokémon who said that camp, to him, means a place to be silly with his friends. It is clear that the opportunity to make friends and engage with peers is something that the participants of the current study valued. Specialised recreational programs should include opportunities to learn social skills and both integrated and disability-specific programs should provide youth with neurobiological disorders the chance to play, interact, and make friends with peers.

There are also implications and recommendations specifically for Camp Neuro as a result of this research. Nick talked in his interview about his struggle with other campers when he was younger. He described one cabin-mate specifically who used to scare him, and Nick attributed his fear to a lack of understanding about "these medical problems". Camp Neuro welcomes a high-needs population, many of whom express challenging behaviours including aggression towards objects and people. While Nick was the only participant who talked about feeling scared of other campers during his interview, it is unlikely he is the only camper who has ever felt this way. It would perhaps be beneficial for Camp Neuro to brief campers on the first day at camp about the diversity of people, behaviours, and communication styles that they may see. Open dialogue regarding the diversity of campers would provide children with an opportunity to ask questions of staff if they have any and may reassure campers that staff are prepared and knowledgeable. Additionally, an up-front discussion may reduce feelings of fear, anxiety or surprise that might arise for campers who are experiencing and witnessing these behaviours for the first time.

Camp Neuro describes its program as a place for children and adolescents with neurobiological disorders to learn social and recreational skills. While the purpose of the current study was to explore what summer camp means to adolescent participants, the results do validate the aim of Camp Neuro's program and suggests that this aim is meaningful to the teens themselves. The research conducted with Camp Neuro provides insight from their campers about what activities are enjoyed and what are meaningful lessons that they have learned through their participation at camp. The evidence also shows that the skills that the campers are learning at summer camp are not only helping them to be successful in the camp environment, but also in other areas of their lives. The *Life Lessons* that some of the participants discussed point to deeper

insights that go beyond their time at summer camp. Additionally, the findings provide Camp Neuro with researched results to apply for funding for their program backed by an evidence-based thesis that characterises their program as something more than just an opportunity for respite for caregivers. Camp Neuro has already requested and been provided data to support a grant application, as per the Laurentian Research Ethics Board approval and parental consent agreements.

4.4.2 Implications for Research

Similarly to the implications for practice, researchers must also re-evaluate what it means to conduct inclusive or accessible research. Flexibility was incredibly valuable and important to the current study over the entire research process. Working with youth with neurobiological disorders requires that researchers be prepared to change and adapt their design in order to accommodate the needs of the participants. For example, while it was initially proposed that each participant who wanted to take part in an interview would select five photographs to discuss, it was evident early on that this was a limitation that did make sense to the participants and that many wanted the opportunity to discuss all of their photographs. Similarly, the schedule at Camp Neuro is very busy and the campers have many activities available to participate in each day. While the teens are able to select their own schedule and the research design had always ensured that participants could choose the day, time and location of both their photo-taking and their interviews, it was still challenging to schedule the research activities. Many of the participants prefer to maintain an identical or similar schedule each day. Others were concerned about missing out on preferred activities. One potential participant declined to take part in the project because it was her last year at Camp Neuro and she had too many other things she wanted to do.

Accommodations were made wherever possible over the course of the project and every effort was made to say yes to the ideas, suggestions and requests of the participants in order to have the research suit their needs. However, working with the time constraints where each participant was only available for two weeks was challenging. Engaging youth with neurobiological disorders in research and working within a highly structured environment such as summer camp require researchers to be prepared to adjust their plans and expectations continuously. Projects that will include this population and that will work in these types of structured settings should ideally ensure flexibility in both their time and their research methods.

Researchers who are engaging in topics that will influence decisions affecting the lives of individuals with neurobiological disorders should consider arts-based qualitative methods such as photovoice to engage individuals with neurobiological disorders in research. Photovoice was an extremely effective method and helped to shape a research project in which participants were enthusiastic to participate. Additionally, a strengths-based approach was informative and beneficial to this study. While participants were prompted to discuss both what they like about summer camp as well as what they find challenging, the overall focus of the participants was strengths-based. Nine of the 13 participants did discuss challenges they experienced at summer camp, but the majority of these references were in response to a probe asking directly about the challenges of camp. Alternatively, the majority of the discussions of the benefits were unprompted. There were only 14 total references to challenges, which represents a very small proportion of the interviews. This study demonstrates the success of engaging youth with complex neurobiological disorders in an arts-based and strengths-based research project.

Future research with vulnerable and high-needs populations should focus on amplifying their voices in an effort to inspire meaningful change to the benefit of the participants. Clinical

and medical research is of course valuable to the field of neurobiological disorders but should be further complemented by qualitative research that explores the lives of individuals with neurobiological disorders in their own words. Additional research that explores fun and meaningful activities to engage high-needs youth should be pursued in order to expand the options for youth and to develop recommendations for recreational service provides to engage a frequently excluded population.

Finally, future research with individuals with neurobiological disorders should be both sex- and gender-informed. While the current study was not sex or gender focused, gender information was collected and discussed (Mandy & Lai, 2017). The perspectives of girls and women with neurobiological disorders is lacking in research and is crucial for an informed understanding. Additionally, the manifestation of neurobiological disorders in biologically female individuals is very different from biologically male and affects diagnosis, treatment, and services, which highlights the important of considering sex (Loomes et al., 2017). Further, gender variance is significantly high in the autism community, as well as other individuals with other neurobiological disorders, in comparison to the general population (Strang et al., 2014). Gender-informed research should acknowledge and validate the existence of gender variance in individuals with neurobiological disorders and use appropriate language, such as the term gender as opposed to sex in demographic reporting, to include a diverse population in research that affects their lives.

4.5 Knowledge Translation

Knowledge translation (KT) is a term coined by the Canadian Institutes of Health Research (Canadian Institutes of Health Research, 2004). The concept refers to the transfer of research findings into practice (Graham et al., 2006). KT focuses on the value of translating

research to diverse audiences for the application of research rather than the idea of research for research's sake (Graham et al., 2006). KT for this thesis project will take several forms. Overall, the goals of KT for this thesis project are to increase decision-makers' knowledge of the experiences of youth with neurobiological disorders in recreation, and to encourage decision-makers and academics to consult with individuals with neurobiological disorders to inform future research, programs, and services. It is important that the relevant messages from this research be communicated to the appropriate audiences in a way that will be understood and will inform future decisions and actions (Liebenberg, 2018). By dividing the KT of this research into three groups, both the information and the communication strategy can be adapted to meet the needs of the population and have the greatest impact. First, the social action component will involve the dissemination of results to decision makers involved directly with Camp Neuro. Social action is a valuable part of photovoice research that ensure the results are implemented in a meaningful way to bring about change to benefit the participants (Liebenberg, 2018; Wang & Burris, 1997). Second, a summary document will be used to communicate the results to similar recreational programs across Ontario and Canada. Finally, publication of the results of the thesis will inform the academic sphere in an effort to encourage further studies. Multifaceted communications have been shown to be more consistently effective for KT (Sudsawad, 2007).

At this stage, the social action component of this project is ongoing and incomplete. While this does not follow the typical, linear style of a master's thesis, it is consistent with KT's characteristics of involving diverse knowledge user groups and encompassing an interactive process (Sudsawad, 2007). The social action component is also an essential feature of photovoice. This component will involve further engagement with the thesis participants and Camp Neuro. In conjunction with the participants, an exhibit will be prepared to display the

photographs and some of the quotes to the Camp Neuro community. The intended audience will include the camp community including campers and caregivers, the full-time staff associated with Camp Neuro, the board of directors and past, current, and prospective donors. The goal of the exhibit will be to communicate directly to the decision-makers of Camp Neuro regarding what the participants value about their time at camp as well as what they find challenging.

The second method of KT will be a one-page summary of results to distribute to recreational programs in Ontario and Canada. The intent for this aspect of KT is to reach the recreational and summer camp community beyond just Camp Neuro in a dissemination style that is non-academic. The one page will resemble an infographic that will represent the results from the current study. The material will aim to highlight suggestions for recreational programs to increase accessibility for youth with neurobiological disorders and the aspects of participation that youth with neurobiological disorders value. Dissemination will occur through relevant website postings and potentially in partnership with Canadian Camping Association and Our Kids.

The third and final method of KT will involve dissemination of results as published articles in academic journals and presentations at relevant academic conferences. This method of KT aims to communicate with academic audiences in order to influence future research. While the results of the current thesis are applicable here as well, it is likely that it is the methods that will be most informative. The methods developed in this thesis worked with youth with neurobiological disorders to understand their experiences at summer camp, which is a unique perspective often overlooked in academia (Jurkowski, 2008). Publication of the current study will influence future research in the area of accessible recreation as well as highlighting the benefits of photovoice research with teens with neurobiological disorders.

While ensuring that meaningful KT occurs is challenging both in time and resources, it is a crucial aspect to research. In particular, because this thesis engaged with participatory methods, the mobilization of results to benefit the lives of the participants is fundamental to the success of the project. The movement of information from knowledge producer, the researcher, to knowledge users, relevant stakeholders, is exciting for the future of inclusive recreation and neurodiversity in research (Graham et al., 2006).

4.6 Conclusion

This thesis aimed to explore what attending a disability-specific summer camp means to adolescents with neurobiological disorders in order to better understand what youth enjoy about their time at summer camp and what they find challenging. The photographs and interviews with a diverse group of adolescents with a variety of complex neurobiological disorders suggest that specialised summer camp programs go beyond providing respite for caregivers to providing meaningful opportunities and experiences to the participants themselves. The teens discussed opportunities to have fun, meaningful relationships with staff and campers, and incredible life lessons that Camp Neuro had given them. The participants of this research project are a high-needs population with complex needs and intense behavioural challenges who are frequently excluded from recreational spaces, social relationships, and academic research. This project demonstrated that with individualised supports and room for accommodation, teens with neurobiological disorders benefit from summer camp by learning new skills, making friends, and having fun outside. This project also showed that with flexibility, youth with neurobiological disorders can contribute meaningfully to research and provide rich insights into their experiences.

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Appendix A- Letter of Information

Letter of Information

Your teen is being invited to participate in a research project titled *Exploring the Meaning of Summer Camp with Teens with Neurodevelopmental Disorders* happening this summer at Camp Winston. Neurodevelopmental disorders include autism spectrum disorder, FASD, ADHD, Tourette's Syndrome, among others. My name is Jenna Simpson and I am a master's student at Laurentian University. I have worked at Camp Winston for the past four years and am currently a member of the senior staff team. This summer I will be collecting data at Camp Winston as part of my thesis research. While Camp Winston is supporting my research, this project is not being conducted by the camp. This summer, I am working as a staff supervisor in the camper program, and not directly with the teen program.

The research project will take place this summer and will involve the teens taking pictures around camp of what summer camp means to them. All campers aged 14-17 that a neurodevelopmental disorder are invited to participate.

Phase 1: Taking photographs of what summer camp means to them.

All of the teens with parent/guardian consent for phase 1, and who express interest in participating will be invited to take photos of camp with supplied digital cameras. Your teen will be supervised and supported through their photo taking by their regular camp counsellors. They will receive a short training session on how to use the camera and focus their pictures, and they will have the chance the practice taking a few photos. They can take pictures of places or activities they enjoy, or things they think should be changed at camp. Below is a copy of the rules that your teen will be asked to follow while taking their photos. Any photographs that do not follow these rules will be deleted.

RULES FOR TAKING PICTURES

1. **Be careful when taking your photos. Make sure that you are safe and if you need help getting a photo, ask Jenna or another counsellor.**
2. **You can take photos of whatever you want, but please respect other people's privacy and do not take photos of people's faces.**
3. **Take photos of things around camp that are meaningful to you such as places, objects, or activities. Do not take photos that are inappropriate such as bad**

Phase 2: Talking about the photos they took in phase 1.

Time constraints mean that I cannot talk to every teen about their photos. Four participants from each session with parent/guardian consent for phase 2 will be randomly selected for an interview during the second week to talk about the pictures they took. Interviews will be audio recorded with parent and participant permission so that I can reference exactly what your teen said as I proceed with the research. This part of the project involves having them select five of their photos from phase 1 that they want to talk about and scheduling an interview on camp property for about one hour.

The rest of the time, your teen will participate in camp activities as usual.

Voluntary Participation

Your teen has the right to decide if they would like to participate in this research. I will talk to them throughout the process to make sure that they also understand this right. The decision to participate in this project will not affect yours or your teen's relationship or future with Camp Winston. I will use various methods to ensure that your teen fully understands their rights such as written and verbal communication, and the use of visual step pictures according to their individual communication needs.

Risks & Discomforts

In discussing what summer camp means to them, your teen may talk about past trauma or difficult circumstances in their lives. These conversations may be emotionally taxing for participants and they may experience strong feelings of discomfort or sadness. If your teen experiences any unpleasant feelings during the project, they will receive emotional support from myself and other camp staff. I will be there to support them through the interview process, and camp counselors and directors will be available afterwards for any additional support they need. I will inform you right away of any emotional upset during an interview and your camper will be able to call home if they would like.

Benefits of Study Participation

The direct benefit for your teen of participating in this study is the chance for them to talk about their summer camp experiences and share their feelings. They will also have the chance to tell their own story through photo taking. Participants who were involved in phase 2 of the project will be invited to a brainstorming even in December to talk about some of the themes from the research. Additionally, all of the teen will be invited to help present the research in its final form at an exhibit in the spring. With the two added events after the summer, your teen also has the option of influencing the project from start to finish.

There may be indirect benefits for summer camp programming. The information from this study will increase knowledge about what the experiences are for teens with neurodevelopmental disorders at summer camp and may influence future decisions about summer camp programs.

Data Storage & Confidentiality

All of the information from this study including the researcher's copy of consent forms, the photographs and audio recordings of the interviews will be kept safe with physical copies held in a locked file at Camp Winston and then in a graduate student office space at the University, and digital copies will be stored on a password protected computer and then uploaded to a secure file server as soon as possible and deleted from the computer. This information will be kept by me for three years, and the pictures your teen may be asked to submit for the interview and transcripts of interviews will be securely stored indefinitely in case of future questions about the research. Your teen's name will not be on any of the information or photos. Any presentations or publications will not include any identifying information and Camp Winston will not be referred to by name. Confidentiality will be protected as much as possible and will be respected throughout the research process and any potential publications. If there are reasonable grounds to suspect that a child has been abused or neglected I will contact the local Children's Aid Society immediately and the camp director will be informed as stated by Camp Winston policy.

Questions & Contact Information

You do not have to decide today whether or not you agree to have your teen participate in this research. The principal researcher for this project is Jenna Simpson. If you have any questions or concerns, you may contact her at jsimpson@laurentian.ca. You can also contact her supervisor, Nicole Yantzi, at 705-675-1151, ext. 3355 or toll free at 1-800-461-4030, ext. 3355.

You may contact an official not attached to the research team regarding possible ethical issues or complaints about the research itself at the Research Ethics Office of Laurentian University, telephone: 705-675-1151 ext. 3213, 2436 or toll free at 1-800-461-4030 or email ethics@laurentian.ca.

Thank you for your consideration,

Jenna Simpson

Appendix B- Parental Consent Form

I have read the above information. I have asked any questions I have about the research study and understood the information.

Participant's Name (Camper): _____

Date of Birth: _____

Medical Diagnosis (check all that apply):

- ☐ Autism Spectrum Disorder (including Asperger's and PDD-NOS)
- ☐ ADHD
- ☐ ODD
- ☐ Tourette's Syndrome
- ☐ Other (please specify): _____

Since this research has different parts, please check all that you agree to have your teen involved in:

- ☐ I agree to have Jenna Simpson talk to my teen and invite them to be involved.
- ☐ I agree to have the pictures taken by my camper used for the research project. (Phase 1)
- ☐ I agree to have my teen talk about the photos they took at camp. (Phase 2)
- ☐ I agree to have the words of my camper recorded on a digital recorder. (Phase 2)
- ☐ I agree to allow Camp Winston to use quotations for the purpose of marketing.

Parent/Guardian's Name: _____ Date: _____

Signature of the Investigator (to be completed once returned): _____
Date: _____

Please send completed consent forms to Jenna Simpson at jsimpson@laurentian.ca or in person on drop-off day. You may also submit forms by mail to the research supervisor at:

Nicole Yantzi
School of the Environment
935 Ramsey Lake Rd.
Sudbury, ON
P3E 2C6

Appendix C- Participant Assent Script

This assent script will be used with the potential participants themselves at the study site. I will only speak to those who have received written consent from a guardian. Vocabulary may be adjusted slightly depending on the cognitive level of the participant.

Hi, I'm Jenna. I want to tell you about a research project that I'm working on. I want to learn about what summer camp means for you and I want to hear from you because you are in the teen program here at Camp Winston.

What I will be asking you to do is take pictures around camp of what camp means to you. It can be things you like, things you'd like to change, anything that means something to you. You can take the pictures any time this week by signing a camera out from the office. Once you've taken all your pictures, I will print you a copy of your photos.

Of all the people taking pictures this session, four will be picked randomly for an interview. If your name is chosen, you can tell me about your pictures, and I'll have a few questions to ask you too. This will be recorded so that I can listen back later and know exactly what words you used.

Your parents/grandparents/the people taking care of you know that I invited you to work on this project and they have said its okay, but you also get to decide if you want to do this. It is totally up to you whether you want to participate in this project. If you don't want to, it won't change anything about your time at camp. Even if you say yes today, you can change your mind later. All you have to do is let me know. And if you have questions about the project, you can ask me. You can also call your parents/guardians if you'd like to talk to them first.

Does that make sense?

Do you have any questions?

Would you like to do take pictures?

If you are randomly picked, would you like talk to me about them?

End of verbal script.

To be completed when obtaining verbal assent:

Participant's response: Would you like to take pictures? ___ Yes ___ No
Would you like to talk to me about them? ___ Yes ___ No

Participant's Name: _____

Researcher's Name: _____ Date: _____

Appendix D- Visual Schedule for Participant Assent

The same assent script will be used, but with the addition of a visual schedule to aid participants who may have difficulties with verbal communication.

CAMP SCHEDULE

DAY 1	Come to Camp Neuro (Recognizable camp logo inserted here)
DAY 2	
DAY 3	
DAY 4	
DAY 5	
DAY 6	
DAY 7	
DAY 8	
DAY 9	
DAY 10	
DAY 11	
DAY 12	
DAY 13	
DAY 14	Go home. 

taking pictures

talk with Jenna

Appendix E- Individual Interview Questions and Probes

Opening Question

- Tell me about your photos.

Follow-Up Questions

- Why did you take this photo?
- What does this photo represent about camp for you?
- How does this photo make you feel? (Stickers of emotion faces, happy and sad, may be used here to help the participants make the connection between photos and emotions, and share their experiences)
- Would you have taken different photos when you were younger at Camp Winston?
- Are there things at summer camp that you'd like to change?
- Looking at this photo, is there something you would change about what's in it?
- If there a photo you wished you'd taken but didn't? What would it have been?

Appendix F- Laurentian Ethics Approval

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New **X** / Modifications to project / Time extension

Name of Principal Investigator and school/department	Jenna Simpson (PI), Faculty of Health\School of Rural and Northern Health; Nicole Yantzi (Supervisor), Environmental Studies/ECHO
Title of Project	Exploring the meaning of summer camp with teens with neurodevelopmental disorders
REB file number	6013794
Date of original approval of project	May 20, 2018
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on: *(You may request an extension)*	May 20, 2019
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Susan Boyko, PhD, Vice Chair, *Laurentian University Research Ethics Board*